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| Subject: | The 2021 Long-Term Care Report: Trends, challenges and opportunities in an ageing society<br>- Country profiles |

Delegations will find attached the country profiles (Volume II) on the subject under reference, established by the Social Protection Committee (SPC) together with the Commission. Volume I (full report) is contained in doc. 9144/21 ADD 1.

The key conclusions which are drawn from this report are contained in doc. 9144/21 and are submitted to the Council (EPSCO) with a view to the meeting on 14 June 2019.

# 2021 Long-Term Care Report

## Trends, challenges and opportunities in an ageing society

# Country profiles

***Volume II***

*Joint Report prepared by the Social Protection Committee (SPC) and the European Commission (DG EMPL)*

2021

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# BELGIUM

***Highlights***

- Belgium has a well-developed system of social protection for (older) people in need of long-term care (LTC). However, differences may appear increasingly between regions, as a result of continual state reforms. e.g. next to the former (now decentralised) care allowances, Flanders created a specific care allowance (*Zorgverzekering*), that is now integrated in its so called *zorgbudget* care allowances.
- There is a movement to deinstitutionalise LTC in order to resolve multiple problems, among them the expected shortage of nursing home beds in the coming years (if current policies remain unchanged). This means more needs to be done to organise LTC at home.
- In recent years, Belgium launched the process of reforming the practice of health care professionals, implemented the BelRAI assessment tool, implemented the reform 'integrated care for better health' to improve the care for people with chronic disease and a new status for the informal caregiver was approved by the federal parliament in 2019.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The ageing of the Belgian population is a major challenge for the future, particularly in Flanders. In 2019, 2.2 million people were aged 65 and over in Belgium, representing 18.9 % of the country's population. 8.8 % of the whole population is aged 75 and over.[1] This rate is expected to increase to 22.6 % by 2030 and to 26.3 % by 2050 for those aged 65 and over. For those aged 75 and over this rate is expected to increase to 11.0 % by 2030 and to 15.3 % by 2050. These rates are slightly lower than the EU average. They differ across the three regions of Belgium, with a younger population in Brussels and the oldest population in Flanders[2].

According to the 2021 Ageing Report[3], the number of potential dependants in Belgium in 2019 is estimated to be 992,200 (8.6 % of the total population) and it is expected that the number of people in need of LTC in Belgium will increase to 1,226,600 in 2050, which would represent 10.3 % of the population. This proportion is higher than in the average EU-

[1] All data used in the text come from Section 5 'Background statistics' unless explicitly stated otherwise.
[2] Devos, C., Cordon, A. and Lefèvre, M., *Performance of the Belgian Health System – Report 2019,* KCE, 2019. https://kce.fgov.be/en/performance-of-the-belgian-health-system-–-report-2019 (accessed 3 April 2020)
[3] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

27 population. The old-age dependency ratio is expected to increase by 51.9 % by 2050[4]. However, this increase is expected to be lower than the European average.[5] Given the differences stated across Belgium, the share of the population in need of LTC is likely to be higher in Flanders and Wallonia than in Brussels.

## 1.2 Governance and financial arrangements

Long-term care (LTC) in Belgium has a fragmented governance structure. After the 6th state reform 2014, the transfer of competencies resulted in a shared ownership of regulation, organisation and financing of home and residential care for older people, health care and social care between the federal level and the federated entities (regions and communities). This is to be managed through coordination between federated entities and the federal level (inter-ministerial conference, inter-administration coordination structures…).[6]

After the 6th state reform, the federal level remains responsible for the financing of social security's healthcare insurance and regulations for the professions. Financing health insurance as a part of social security is organised through the so called 'global financial administration' social security mechanism, administered by the National Office for Social Security (NOSS). Financing of social security is based on social contributions, subsidies from general taxation and earmarked taxation. The reimbursement of healthcare is administered by the National Institute for Health and Disability insurance (NIHDI or RIZIV-INAMI). This includes reimbursement of medical and health related care, including long-term health care in institutions, at home or in doctors' surgeries or hospitals by health professionals such as nurses, medical doctors, physiotherapist, etc.)[7].

Regulation of the medical professions providing healthcare (physicians, nurses) is the responsibility of Federal Public Service Health, Environment and Safety of the Food Chain[8]. Regulation of other professions providing social care at home (i.e. family help) are the responsibility of the federated entities (regions and communities). These are also responsible for financing and regulating nursing homes, homecare, organising the coordination of care, organising and supporting the development of primary care. Besides receipts out of their own fiscal competences, the regional entities are financed partly through so called *dotations* out of the total general fiscal receipts, linked to the size and characteristics of their population.

Complementary to LTC, a system of social service acquisition is available for the entire population through the so called 'service voucher' system. The financing of the voucher system, which is open to everyone and which includes a number of personal services defined by law like cleaning, ironing and washing laundry, preparing meals (at home), shopping (post office, bakery, pharmacy…), transportation for vulnerable groups (invalid or people with

[4] Eurostat data: proj_19ndbi.
[5] European Commission, 'The 2018 Ageing Report - Underlying Assumptions and Projection Methodologies', *Institutional Paper 065*, European Commission, Brussels, 2018.
[6] Devos, C. et al., 2019.
[7] Gerkens, S, *The Health Systems and Policy Monitor*, 2013. http://www.hspm.org/countries/belgium25062012/countrypage.aspx.
[8] Pacolet, J. and De Wispelaere, F., *ESPN Thematic Report on Challenges in Long-Term Care Belgium*, European Social Policy Network (ESPN), European Commission, Brussels, 2018.

disabilities), is another responsibility transferred to federated entities. The public contribution for this system represents 0.16 % of GDP, topping up the traditional LTC benefits by another 10 %[9].

As a consequence of the increased responsibilities for the federated entities[10], existing structures at the federated level have been reinforced (e.g. the Flanders Agency for Care and Health (VAZG)) or new structures have been created in each of the regions and communities to assume new responsibilities: the Flemish Agency Social Protection, in Wallonia, the *Agence pour une Vie de Qualité or AVIQ* and in Brussels, Iriscare (i.e. the administration) and BRUSANO (an organisation supporting primary care provision).

In Flanders, the VAZG is the organisation with overall responsibility for health and social care matters. For LTC, it is responsible for the planning, licensing and financing of nursing homes, and also for regional responsibility for homecare. The *Vlaamse Sociale Bescherming* (VSB) (Flemish Social Protection) is responsible for the financing of the benefits in cash or in service vouchers (since the transfer of the voucher system mentioned above). Since 1 January 2019, nursing home funding is also done through the VSB. The VSB is partly funded through retributions and partly through subsidies from the Flemish governments' budget.

In Wallonia, AViQ was created in 2016. It has responsibilities for health and long-term care for people with disabilities and older people, including the employment policies for people with disabilities, care allowance for dependent older people, home care and care homes for older people, and also family benefits[11]. Since 1 January 2019, AVIQ has been responsible for funding nursing homes.

The German-speaking community (GC) is geographically part of the Walloon region. However, it has its own governance structure[12] for its responsibilities, including care for older people and people with disabilities. The administration of LTC is done by the *Dienststelle für ein selbstbestimmtes Leben*. This agency administers cash benefits and services.

Similar to VAZG in Flanders and AVIQ in Wallonia, IRIScare has been created in Brussels to manage the responsibilities that were transferred to the Brussels region. However, the duties (including the organisation and support to primary care) are under the responsibility of the Common Community Commission (CoCom)[13]. A new organisation, BRUSANO, was created from the previous ones (SISD, RLM-B, plateforme de soins palliatifs, etc.). Its function is to support the organisation, coordination and development of primary care in the Brussels region[14] and simplify the use by patients.

[9] Pacolet J. and De Wispelaere, F., 2018.
[10] For regional entities, the responsibilities may be partially new, but they existed federally.
[11] Pacolet J. and De Wispelaere F., 2018.
[12] Probis, *Le Secteur Des Maisons de Repos Sous La Loupe : Tendances, Défis et Indicateurs*, 2017.
[13] Pacolet J. and De Wispelaere F., 2018.
[14] https://brusano.brussels/

## 1.3 Social protection provisions

Belgium has a well-developed system of social protection for (older) people in need of LTC. This is due to a strong social insurance system at federal level. However, differences may appear between regions, as a result of the progressive state reforms.

At federal level, social security health insurance ensures the financing of nursing (including LTC) and other healthcare services at home. People in need of long-term home care, as it is the case for each citizen, are entitled to a reimbursement of their healthcare. This is more favourable for some groups than others. This covers all or part of the cost. The level of reimbursement of care is, amongst other things related to the (dependency) status of the beneficiary (a higher level of dependency gives entitlement to higher reimbursement levels). Other groups of people entitled to higher reimbursement rates include those on low income or with a specific social status (e.g. widowed, people with disabilities). Health insurance also has specific levels of reimbursement for those who are chronically ill, or things like incontinence material. There is also a 'maximum billing' of care payment above which people are exempt from further out-of-pocket payment, depending on their income[15].

At regional level, residential services (nursing homes) receive a flat rate of funding that includes a daily price and infrastructure subsidies. This is adjusted depending on the level of dependency of the resident. Additionally, there is a price per day regulated by the regions to be paid by the resident (e.g. for catering, social activities). However, additional fees can be charged to residents for things like washing clothes, watching TV, medication.

Beside those services, there are some regional differences for homecare services. Wallonia and Brussels finance coordination centres with care coordinators through a fixed budget. This service is free-of-charge and assists people with complex health and social care needs to find appropriate services. In Flanders, social workers from sickness funds, local[16] and regional service centres can also help people in accessing (social and homecare) services[17]. In Brussels, Wallonia and Flanders, the cost for homecare social services is related to the beneficiary's income[18].

The cash benefits policies for Wallonia, Brussels and Flanders differ, even if they have similar approaches. In Flanders, the former *zorgverzekering* and the former federal allowances were integrated into the *zorgbudget* system, with different levels of benefit depending on income and (care) needs. In the other communities (French and German speaking), the formerly federal rules have been continued under their jurisdiction In Brussels, Iriscare is responsible for delivering these in-cash benefits to older people (APA / THAB). In Wallonia, it is administered by the AVIQ and by the *Dienststelle für ein Selbstbestimmtes*

[15] INAMI, *Facilités Financières Pour Payer Vos Soins de Santé - INAMI.*
[16] Vlaanderen, *Lokale Dienstencentra,* https://www.vlaanderen.be/gezondheid-en-welzijn/gezondheid/thuiszorg/lokale-dienstencentra (accessed 26 April 2020)
[17] Vlaanderen, *Diensten Voor Gezinszorg en Aanvullende Thuiszorg,* https://www.zorg-en-gezondheid.be/per-domein/thuiszorg/diensten-voor-gezinszorg-en-aanvullende-thuiszorg (accessed 26 April 2020)
[18] Iriscare, *Services d'aide à Domicile - Aides et Soins - Citoyens*.

Leben in the German speaking community. These in-cash benefit aims provide beneficiaries some freedom to choose their mode of care and assistance[19].

## 1.4 Supply of services

LTC services include residential services (nursing homes), day care centres and services to assist people at home.

There was a total of 147,580 beds available for residential services (nursing homes) in Belgium in 2018[20]. Brussels is the region with the highest rate of beds per population aged 65 and over (99 beds/for every 1000 people aged 65 and over) followed by Wallonia (74), Flanders (61) and the German-speaking community (50). The occupancy rate in the public sector of higher care beds (i.e. beds with more nursing support) in nursing home was 100 % in Wallonia and 94 % in Brussels[21]. Unlike the other regions, Brussels had a surplus of nursing home beds. In 2016, there were more than 2600 vacant places in homes for older people. As a consequence, the regional government introduced on a moratorium on opening new nursing home beds.

In contrast to the situation in Brussels, the overall numbers of beds available in the other regions, and therefore in Belgium as a whole, is judged insufficient if projected needs are to be covered (particularly for higher care beds for highly dependent people). Indeed, according to a model developed by the Federal Planning Bureau, 149,000 to 177,000 beds are estimated to be needed in 2025. After 2025, the increase in need is projected to accelerate further[22].

In relation to ownership, data from 2019 shows that 17 % of the nursing homes in Flanders are privately owned, 27 % are public, and 56 % are owned by non-for-profit organisations. In Wallonia, a decree defines the share of beds between public sector (29 %), non-for-profit sector (21 %) and private sector (maximum 50 % and in reality 48 %). In 2018 in Brussels, 63 % of the nursing home beds were privately owned by four multinational companies who share the 'market'. Furthermore, 24 % of the nursing home beds are public, and 13 % are owned by non-for-profit organisations[23]. The government of Brussels aims to reset the balance of the share between private, non-for-profit and public ownership of nursing home beds.

Provision of LTC at home in Belgium consists of a combination of day care centres, nurses and social services (homecare). Day care centres (specifically for older people, and often part of nursing homes) are an alternative to residential care for dependent people (particularly for those with cognitive deficiencies). There were 2.5 places for every 1000 people aged 75 or more in 2011[24]. Nurses play a key role in LTC at home (nursing aids or family help assistants providing essentially personal hygiene support). In 2016, there were 6254 full-time

[19] Vlaanderen, *Zorgbudget Voor Ouderen - Vlaamse Sociale Bescherming*. https://www.vlaamsesocialebescherming.be/zorgbudget-voor-ouderen-met-een-zorgnood (accessed 26 April 2020)
[20] Devos, C., Cordon, A. and Lefèvre, M.
[21] Vandemeulebroucke, M., *Tirer Les Vieux Du Lit – Alter Echos*. https://www.alterechos.be/tirer-les-vieux-du-lit/ (accessed 26 April 2020)
[22] Van Den Bosch, K. et al., *Residential Care for Older Persons in Belgium: Projections 2011 – 2025*, ed. by KCE, 2011.
[23] Vanderbecq, P., *Analyse Des Prix: Rapport Annuel 2018 de l'institut Des Comptes Nationaux,* Brussels, Belgium, 2018.
[24] Van Den Bosch K. et al., 2011.

equivalent nurses (FTE) providing care at home[25]. This corresponds to 0.6 FTE home nurses per 1000 inhabitants. Nursing care is provided by nurses employed by large organisations or by those who are self-employed. In the three regions, the majority of nurses are self-employed: 71.15 % in Flanders, 80.12 % in Brussels and 87 % in Wallonia[26].

Nevertheless the 'cost' of their services are the same. The difference lies in that self-employed nurses are paid directly by the health insurance, while for employed nurses, it is the organisation that receives the payment and will pay a (fixed) wage to the nurses. For the patient there is no difference, except that some sickness funds have arrangements with nursing organisations making the service free for their members (supplementary payment made by the sickness fund).

Social care includes services to help dependent people at home (cleaning, cooking, other household support). In Belgium it is provided by different channels: by municipality public social welfare centres (PCSW or OCMW-CPAS), by non-for-profit organisations linked to sickness funds or through recognised firms using the voucher system (mainly for family help services). Homecare has changed with the implementation of the voucher system. It has drastically reduced the proportion of services provided by the informal sector[27]. In 2017, 25 % of the users of the voucher system for homecare were people aged 65 and over. Among the organisations providing services within the voucher system in Flanders 47 % are private for-profit organisations and 17 % are linked to the PCSW. In Brussels, 81 % of services provided through voucher system are through private for-profit organisations. In Wallonia, 44 % of the organisations for homecare using voucher system are private, 9 % are linked to the PCSW and the rest by non-for-profit organisations[28]. Additional to the formal sector, there is a high proportion (20 %) of people aged 50 and over who are informal caregivers in Belgium (9 % on a daily basis and 11 % on a weekly basis).

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

In Belgium, the health insurance system covers health care in nursing homes (residential care) and at home. The level of reimbursement available depends on the degree of support required for daily life activities and the cognitive status[29]. In 2018, 13.6 % of the population aged 65 and over received formal LTC: 8.5 % in residential facilities and 5.1 % at home[30]. This is close to the OECD average[31]. These proportions increase steeply with the age: 1 % of

[25] Vivet, V. et al., *Infirmiers Sur Le Marché Du Travail, 2016 Résultats Du Couplage Des Données Plan CAD SPF SPSCAE-Datawarehouse MTandPS-INAMI Un Rapport de La*, 2018. www.health.belgium.be/hwf (accessed 7 April 2020)
[26] Jouck, P. et al., *Infirmiers Sur Le Marché Du Travail, 2017 Résultats Du Couplage Des Données PlanCad SPF SPSCAE-Datawarehouse MTandPS-INAMI Un Rapport de La*, 2020. www.health.belgium.be/hwf (accessed 26 April 2020)
[27] Valsamis, D. and Perin, E., *Evaluation Du Système Des Titres-Services Pour Les Emplois et Services de Proximité En Région de Bruxelles-Capitale,* Brussels, Belgium, 2018.
[28] Ballara and Lamargue, *Étude Préliminaire Les Métiers de l'aide à Domicile*, 2019
[29] Devos, C., Cordon, A. and Lefèvre, M., 2019.
[30] Idem.
[31] Idem.

people aged 65 to 69 receive LTC in nursing home and 1.5 % at home; but more than 40 % of people aged over 90 receive LTC in nursing home and 14 % at home. Women receive more care than men (11 % vs. 5.2 % in residential care; 6 % vs. 4 % in care at home). The socio-economic status also a factor: 16.2 % of the BIM population [increased assistance beneficiaries for people with a lower socio-economic status] receive residential care vs. 5.3 % of the non-BIM population. 9.3 % of BIMs receive care at home vs. 3.4 % of non-BIMs.

There are also differences between regions, depending on the financial support granted by the regions. The proportion of older people in residential care is higher in Brussels (10.3 %) and in Wallonia (9 %) compared to Flanders (8 %), while the opposite can be observed for care at home: 3.3 % in Brussels, 4.8 % in Wallonia and 5.5 % in Flanders[32]. Out-of-pocket payment by residents can also differ. There are geographically differences, but also differences between and within for profit and not-for-profit providers, and between and within public and private providers. In the second half of 2017, it was estimated on average at EUR 47.76 per day in Wallonia[33] , EUR 53 per day in Brussels and EUR 60 per day in Flanders[34]. Monthly average out-of-pocket payments for accommodation (accounting for 93 % of the total cost) was EUR 1333 in the public sector, EUR 1350 in private sector and EUR 1450 in the non-for-profit sector[35]. Regarding homecare, 24.4 % of households in need of LTC in Belgium report not using professional homecare services for financial reasons, and 5.8 % because the service is not available[36].

## 2.2 Quality

The quality of LTC is ensured through initiatives and laws at different levels of governance and for different sectors or professionals.

At federal level, healthcare professionals are regulated through the Ministry of Health and Social Affairs and as explained above.

To improve the quality of services within nursing homes, various new decrees have been approved, mainly in Flanders and Wallonia. In Flanders, a new 'Woonzorgdecreet' was approved in early 2019. It sets out standards and criteria for nursing homes with the aim to protect quality of life of older people living in these facilities. Generally speaking, quality in nursing homes is ensured through inspections, but also through set standards. In Flanders, these standards are related to the quality decree of 2003 setting the framework and quality criteria and indicators (covering quality of care, safety, providers and organisation quality, and quality of life)[37]. In Wallonia, an update of the 'code wallon de l'action sociale et de la santé' with regard to residential institutions for older people was approved and published at the end of 2019[38]. It includes standards for day care facilities, nursing homes and other

[32] Idem.
[33] Including the German-speaking Community, as mentioned above.
[34] https://www.ing.be/Assets/Documents/Marketing/ING_Probis_FR.PDF
[35] http://solidaris.be/bw/pages/maison-de-repos-a-quel-prix.aspx?choixregion=true
[36] EU-SILC (2016): ilc_ats15.
[37] Vlaanderen, *Kwaliteit in Woonzorgcentra*. https://www.zorg-en-gezondheid.be/kwaliteit-in-woonzorgcentra (accessed 26 April 2020)
[38] AVIQ, Réglementation Applicable à l'hébergement et à l'accueil Des Aînés En Wallonie.

residential facilities for older people, as well as mechanisms of regulation (such as sanctions)[39]. In relation to coordination centres (with coordinators for homecare), a licence (accreditation) is awarded to selected organisations to provide coordinated services within the 13 zones (SISD). Criteria to get a licence include the capacity to provide a minimal package of services, guarantee of permanence, professional and organisational standards. The area of practice of the coordination centres takes into account the growth of the population over 60[40]. In Brussels, an ambulatory decree was approved in 2009. This sets up standards and criteria for the organisation of ambulatory care in Brussels, including care coordination, health and social care. This decree was updated in 2019. As part of quality assurance, ambulatory providers are required to follow a specific approach to receive a licence agreement: the process of qualitative evaluation (*la démarche d'évaluation qualitative* (DEQ)).

## 2.3 Employment (workforce and informal carers)

Belgium, like many other countries, faces shortages in the availability of nursing professionals making it hard to find sufficient nursing in all sectors (healthcare and LTC). This common challenge leads to the different institutional sectors acting as competitors on the labour market.

In Belgium, there were 4.8 LTC workers per 100 people aged 65 and over in 2016 (see Section 5 'Background statistics'). This is higher than the EU average (just below 4 LTC per 100 people aged 65 and over in 2016)[41]. Almost all workers are women (93.6 %). Short stay and day care centres mentioned above in the report, play a role in respite care.

In nursing homes, the shortage of nurses is likely to increase in the coming years[42]. This shortage is more marked in Wallonia (9.2 nurses for 30 residents in 2016-2017) than in Flanders (11.2 nurses for 30 residents in 2016-2017).

For homecare, there is also a shortage of nursing staff as well as general practitioners (GP). Despite that shortage, they benefit from better working conditions than the social care sector. There is a high proportion of foreign workers (42 %) employed in homecare work in Flanders. These professionals are mainly women (98 %), older people (25 % are over 50) and low levels of education (60 % had less than a secondary school diploma in 2016)[43].

Informal caregivers like family or neighbourhood help represent an important share of the care (an estimate of 800,000 people)[44].

[39] Wallonie, *Réforme Du Secteur Des Maisons de Repos*, 2019.
[40] Wallonie, *Soins et Aide à Domicile* - Portail SANTE.
[41]OECD, 'Who Cares? Attracting and Retaining Care Workers for the Elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en
[42] ING, *Maisons de Repos: Tendances et Indicateurs*, 2018. https://www.ing.be/Assets/nuid/documents/714429_studie_design_ouderenzorg_FR_pages.pdf (accessed 7 April 2020)
[43] Ballara and Lamargue, *Étude Préliminaire Les Métiers de l'aide à Domicile*, 2019.
[44] Michel, M., *Enfin Un Statut et Un Congé Rémunéré Pour Les Aidants Proches*. https://www.lecho.be/monargent/budget/enfin-un-statut-et-un-conge-remunere-pour-les-aidants-proches/10118082.html (accessed 26 April 2020)

## 2.4 Financial sustainability

As stated previously, following the Ageing Reports' projections, the old-age dependency ratio within those aged 65 and over is expected to increase by 51.9 % by 2050. This would cause an increase in the need for LTC which is expected to increase costs from 2.2 % of GDP in 2019 to between 3.7 % (reference scenario) and 4.4 % (risk scenario) of GDP in 2050 (see LTC table in Section 5). That increase would affect public spending on residential care and on home care in a similar way.

Between 2016 and 2018, in homecare services there has been an increase of more than 3% each year in nursing care costs and more than 2 % for GP costs. The increase in nursing costs is largely explained by the increase of care to highly dependent people (increasing o by 5.3 %). Spending related to nursing care for that group of patients increased by EUR 74.1 million[45].

The 2019 Country-Specific Recommendations (CSR) recommended Belgium to continue reforms to ensure fiscal sustainability for LTC. The analysis points to the fact that 'public spending on long-term care is projected to increase by 1.7 p.p. of GDP between 2016 and 2070, an above average increase starting from what is already one of the highest levels in the Union. The organisational fragmentation of LTC, with responsibilities currently spread across different administrative levels, challenges some dimensions of spending efficiency, hence the net impact of the recent transfer of responsibilities is not yet clear. Strengthening governance would help to achieve the intended efficiency gains. There might be room to optimise the care mix to increase the cost-efficiency of the long-term care system[46/47].

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

The *SFP sécurité sociale* published a report on people with disabilities[48] which sheds light on important challenges for supporting them. One of them is the difficulty of accessing cash benefits: only 10 % of the families with a child with disabilities take up the allowance they are entitled to because of a lack of information or difficulties with the procedures to access the benefits. Furthermore, there is a 'Matthew effect'[49]for people with disabilities: those with the most important needs are those who request the least[50].

Regarding people with severe psychiatric problems, an evaluation of the mental health policies and reforms was performed by the KCE [51] . It reports difficulties in the implementation of the reform (mainly on deinstitutionalisation of LTC for people with severe

[45] Cour des comptes, 176e Cahier – Partie II : Cahier 2019 Relatif à La Sécurité Sociale.
[46] Recommendation for a Council Recommendation on the 2019 National Reform Programme of Belgium and delivering a Council opinion on the 2019 Stability Programme of Belgium, 10154/19, 2 July 2019.
[47] There were no fiscal CSRs in 2020.
[48] Hermans, K. , Dubois, J.M. and Vanroose, A., *Pauvreté et Handicap En Belgique*, SPF securite sociale, Brussels, 2019, p. 285.
[49] The Matthew effect can be summarised by the adage 'the rich get richer and the poor get poorer'. Due to the weight of social and cultural stratification, more vulnerable segments of societies tend to find it hard to access the public services which might lead to an (unintended) adverse redistribution of resources.
[50] Hermans, K. , Dubois, J.M. and Vanroose, A., 2019.
[51] Mistiaen P. et al., *Organisation Des Soins de Santé Mentale Pour Les Adultes En Belgique – Synthèse*, 2019. www.kce.fgov.be (accessed 10 April 2020)

psychiatric problems) including a lack of a common vision between projects and the low involvement of providers outside of the mental health sector (particularly GP).

# 3 REFORM OBJECTIVES AND TRENDS

Although many responsibilities of LTC regulation and financing have been transferred to federated entities, reforms or plans in process at federal level can also have consequences for care provision to people in need of LTC. This process was motivated by an effort to create more homogeneous policy responsibilities.

First, in September 2016, the Belgian Minister of Social Affairs and Public Health launched the process of reforming the practice of health care professionals[52]. The reform is based on three pillars: patient autonomy, collaboration between health care professionals, and the recognition of acquired skills and continuing education of health care professionals. This is the first step in a long process of reform[53]. This reform may have implications on task division and responsibilities between professions. It may respond in part to the challenges posed by the shortage in GPs and nurses at home.

Second, as part of the e-health roadmap 2016-2018, the BelRAI instrument has been implemented. It aims to support the collaboration between providers at home, in nursing home, and across organisations. The ambition is to use this tool in Flanders in all sectors of social protection. In Wallonia, it is also planned to be used by coordinators of coordination centres to assess the status of people at home.

Third, the reform 'integrated care for better health' has been implemented to improve the care for people with chronic disease. Since 2018, 12 projects are working in a local governance structure, testing a series of actions to improve care integration. One of them, case management at home, is of particular interest to improve accessibility to care for people with a loss of autonomy. It was already evaluated in the context of a previous programme.[54]

Fourth, a new status for informal caregivers has been approved by the federal parliament in 2019. It gives extended leave for workers to provide informal care under specific conditions (including providing at least 50 hours per month or 600 hours per year)[55].

The political crisis since January 2019 and the present COVID-19 crisis have brought to the forefront the difficulties linked to the disparity of responsibilities in the policy domain and stressed the problems and challenges linked to it. The COVID-19 crisis led to the creation of a security council composed of all federal and federated governments and the appointment of a COVID Commissioner.

In Belgium, as in many other countries, the high death toll and the way older people died (isolated) in nursing homes, led to severe criticisms about the management of the crisis.

[52] Coordinated law of the 5 October 2015, previously known as Royal Decree No 78.
[53] Gerkens, S., *The Health Systems and Policy Monitor*, http://www.hspm.org/countries/belgium25062012/countrypage.aspx.
[54] Lambert A.S. et al., *Evaluation of Bottom-up Interventions Targeting Community-Dwelling Frail Older People in Belgium: Methodological Challenges and Lessons for Future Comparative Effectiveness Studies*, *BMC Health Services Research*, 2019. https://doi.org/10.1186/s12913-019-4240-9.
[55] https://pro.guidesocial.be/articles/actualites/reconnaissance-et-conge-remunere-pour-les-aidants-proches.html

Residential facilities for older people or people with disabilities received detailed guidelines and tutorials about how to manage infected residents and/or staff members. Nevertheless, as with many other countries during this crisis, problems were encountered with sufficient availability of personal protection equipment, but also with staff shortages linked to the impact of illness or infections[56].

## 3.1 Long-term care in Flanders

In Flanders, a new 'Woonzorgdecreet', approved in early 2019, defines the different components and functions of LTC (and ambulatory care). This includes nursing homes, day care centres, but also social workers from sickness funds, local and regional centres of services. It also aims to clarify the price of services and quality criteria.[57] This is expected to become a central mechanism to organise the coordination between the various stakeholders of health and social care closest to the person with the need. Finally, the 'Vlaamse Sociale Bescherming' (VSB) (Flemish Social Protection) has continued to develop.

## 3.2 Long-term care in Wallonia

In February 2019, the 'plan Papy boom' launched in May 2017, was translated into a law that defines support for older people. It reforms the regulation and financing of the residential care for older people (nursing homes). It includes a new public financing mechanism for the infrastructure, regulation of the daily fee, standards putting the quality of life for residents as a central priority and territorial flexibility for new structures.

## 3.3 Long-term care in the German speaking community

Recent reforms in the German speaking community include the establishment of a German Community Office for self-determined life (*Dienststelle für selbstbestimmtes Leben*), mobility aids and offers to older or dependent people on palliative care.

## 3.4 Long-term care in Brussels

After the creation of Iriscare in 2017 and BRUSANO in 2019, no new reforms have been implemented.

[56] Gerkens and Rondia, *COVID-19 Health System Responses - Belgium*, 2020.
[57] Vlaanderen, *Nieuw Woonzorgdecreet Beschermt Tegen Niet Erkende Initiatiefnemers,* https://www.zorg-en-gezondheid.be/nieuw-woonzorgdecreet-beschermt-tegen-niet-erkende-initiatiefnemers (accessed 26 April 2020)

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

Belgium has a well-developed system of social protection for (older) people in need of LTC. However, some observations mentioned in this report might offer opportunities and challenges.

Access and affordability: According to EU-SILC, it can be concluded that people refrain from using LTC services due to financial reasons.

As ageing continues, Belgium will be facing increasing needs and demand for LTC services, infrastructure needs and the human resources needs will go hand in hand.

According to a model developed by the Federal Planning Bureau, 149,000 to 177,000 beds would be needed in 2025. After 2025, the increase in need is projected to accelerate further. The overall number of beds available in Belgium may thus be considered insufficient if projected needs are to be covered (particularly for higher care beds for highly dependent people).

As in many other countries, increasing demand will also lead to increased need for formal carers, both in institutional and in home care. This will affect workforce planning, including recruitment, retention strategies and, training opportunities.

# 5 BACKGROUND STATISTICS

| *5.1. Demographics* | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 10.7 | 11.5 | 11.8 | 11.9 |
| Old-age dependency ratio, 2019 | | 25.8 | 29.5 | 36.4 | 44.8 |
| Population 65+ (in millions), 2019 | Total | 1.8 | 2.2 | 2.7 | 3.1 |
| | Women | 1.1 | 1.2 | 1.5 | 1.7 |
| | Men | 0.8 | 1.0 | 1.2 | 1.4 |
| Share of 65+ in population (%), 2019 | | 17.1 | 18.9 | 22.6 | 26.3 |
| Share of 75+ in population (%), 2019 | | 8.5 | 8.8 | 11.0 | 15.3 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.6* | 20.6 | | |
| | Women | 21.3* | 22.1 | 23.2 | 25.1 |
| | Men | 17.6* | 18.9 | 19.9 | 21.8 |
| Healthy life years at the age of 65, 2018 | Total | 10.0* | 11.1 | | |
| | Women | 9.7* | 11.4 | | |
| | Men | 10.4* | 10.8 | | |

**data for 2010*

| *5.2. People in need of LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 992.2 | 1,086.3 | 1,226.6 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 479.9 | 591.3 | 767.0 |
| | Women | | 306.1 | 370.5 | 480.0 |
| | Men | | 173.8 | 220.8 | 287.0 |
| Share of potential dependants in total population (%), 2019 | | | 8.6 | 9.2 | 10.3 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 22.0 | 22.1 | 24.4 |
| Share of population 65+ in need of LTC** (%), 2019* | | 36.0 | 29.9 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| *5.3. Access to LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 6.2 | 6.1 | 8.1 |
| Share of population 65+ receiving care at home (%), 2019 | | | 15.7 | 15.8 | 17.8 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 7.8 | 7.7 | 9.2 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 99.8 | 99.5 | 106.3 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 35.3 | 34.8 | 37.6 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | - | - | | |
| | Women | - | - | | |
| | Men | - | - | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 24.7 | 25.1 | | |
| | Women | 28.5 | 29.2 | | |
| | Men | 19.4 | 20.0 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 24.4 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 5.8 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 1,232.5 | 1,276.6 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 4.6 | 4.8 | | |
| | % Women | | 93.6 | | |
| Share of population providing informal care (%), 2016 | Total | | 11.6 | | |
| | Women | | 13.0 | | |
| | Men | | 10.1 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 15.0 | | |
| | Women | | 15.7 | | |
| | Men | | 14.1 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 2.1 | 2.2 | 2.5 | 3.7 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 2.1 | 2.2 | 2.7 | 4.4 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 60.9 | 62.5 | 63.3 | 67.5 |
| Public spending on home care as % of total LTC public spending, 2019 | 39.1 | 26.8 | 26.6 | 24.6 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 0.0 | 10.7 | 10.2 | 7.9 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 2.1 | 2.1 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.1 | 0.1 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# BULGARIA

## *Highlights*

- The population in Bulgaria, in 2019, was estimated at 7 million. The population over the age of 65 according to 2019 data is 1.5 million, showing an increase of 0.2 million compared to data from 2008. The number of potentially dependent people in Bulgaria is 258,500 as of 2019 and the share of potential dependants in the total population is 3.7 %. The share of population 65+ in need of long-term care (LTC), defined as having at least one severe difficulty in personal care and/or household activities, is 27.9 % in 2019.
- To address some of the key challenges in LTC service sector, a comprehensive reform has been launched in Bulgaria, based on the National Strategy for Long-Term Care, as well as the Action Plan for its implementation for the period 2018-2021. The approved action plan for the implementation of the National Strategy for Long-Term Care aims to address some of the major challenges identified in the strategic document for LTC in Bulgaria, such as developing integrated services, quality standards, focussing on prevention and outreach work, etc. The implementation of these measures is yet to be seen and evaluated. An Action Plan for the period 2022-2027 for the implementation of the National Strategy for Long-Term Care is being developed, through which the second stage of the process of deinstitutionalisation of care for people with disabilities and the older people will take place.
- LTC services are divided between the social and health care sectors. In social services, LTC services are provided by specialised institutions, social services for residential care, community-based social services (as daily activities, part-time therapeutic, informative, consultative and other services) and home-based social services. In line with the process of deinstitutionalisation, community based social service for adults, including residential care, have significantly increased since 2012.
- A comprehensive reform of the social services sector was launched in 2019 with the adoption of the Social Services Act which came into force on 1 July 2020. The main objective of the Act is to improve the regulatory framework in social services, with a view to improving the planning, accessibility, management, financing, quality, effectiveness and monitoring of social services.

# 1 DESCRIPTION OF THE MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

## 1.1 Demographic trends

The population in Bulgaria in 2019 was 7.0 million.[58] This represents a decrease of 0.5 million compared to 2008. The old-age dependency ratio was 33.2 % (for 2019) compared to 31.4 % in the EU-27, which signifies an increase in 7.4 p. p. since 2008. Bulgaria's population aged over 65 was 1.5 million in 2019, representing an increase of 0.2 million compared to 2008, 0.9 million of whom were women and 0.6 million men. Regarding the share of 65+ in the population for 2019, it was 21.3 %; representing a rise of 3.5 p.p. compared to data from 2008. This remains close to the EU average of 20.3 %. Regarding the share of 75+ of the population, there has been a rise of 1.2 p.p., reaching 8.8 % of the population in 2019. However, this remains lower than the EU average of 9.7 %. The data gathered by the National Statistical Institute of the Republic of Bulgaria states that life expectancy at birth of the Bulgarian population calculated for the period 2016 - 2018 is 74.8 years.[59] With regards to life expectancy at the age of 65 (in years), there has been a positive increase of 0.7 years - with numbers rising both for women and men between 2008 and 2019 and leading to 16.3 years in total for both men and women. However, the number remains much lower than the EU average of 20.2 years. Regarding the measurement of healthy life years at 65+, there has been an increase of 0.4 years - leading to a figure of 9.8 years as of 2018, close to the EU average of 9.9 years.

The number of potentially dependent people in Bulgaria by data from 2019 is 258,500. The share of potential dependants in the total population is 3.7 %, significantly lower than the EU average of 7.0 % in 2019.[60] However, the share of the population aged 65+ in need of LTC (defined as having at least one severe difficulty in personal care and/or household activities) in 2019 is 27.9 %. There is a projection for a decrease in Bulgaria's population to 6.5 million in 2030 and to 5.7 million by 2050, compared to 7.0 million in 2019. Hence, there is a significant expectancy that the old-age dependency ratio will rise, to 39.0 % by 2030 and up to 55.0 % by 2050. This is 3 p.p. higher than the EU average of 52.0 %. This number confirms the ongoing need for LTC, which will only become stronger in the future. This conclusion is supported by the projected rise in the number of potential dependants to 268,100 by 2050. In addition, projections suggest an increase in the share of potential dependants in the total population, reaching 4.1 % in 2030 and 4.8 % by 2050, as compared to 3.7 % in 2019.

## 1.2 Governance and financial arrangements

LTC services for old people and people with disabilities are provided through two distinct systems in Bulgaria. LTC health and LTC social services are regulated by different bodies

[58] All data used in this report come from Section 5 'Background statistics' unless explicitly stated otherwise.
[59] Information by The National Statistical Institute in Bulgaria, period 2016 – 2018I. https://www.nsi.bg/sites/default/files/files/pressreleases/LifeExpectancy_2016-2018_en_WU64BBF.pdf.
[60] There is no available data specifically for dependents aged 65+ in the background statistics produced centrally by the Commission.

and legislation. Depending on the specific case, LTC is provided by the state, municipal authorities, private providers or social welfare. Currently, there is no separate definition of LTC services in Bulgarian legislation. The adopted Strategy for Long Term Care uses the definition given at EU level. Social services are regulated by the Social Services Act (SSA).[61] Health services, on the other hand, are regulated by the Medical Treatment Facilities Act and are provided through different types of institutions such as hospitals for further and continuing treatment, hospitals for rehabilitation and hospices. The package of health activities guaranteed by the state budget also includes clinical pathways for long-term care. They provide long-term treatment and early rehabilitation after some serious medical conditions and illnesses, palliative care for patients with oncological diseases, physical therapy and rehabilitation of diseases of the central and peripheral nervous system etc. Physical therapy, rehabilitation and specialised care for persistent/chronic/ vegetative conditions are also paid for by the state. In order to improve the access to health services, a number of measures have been taken in recent years, including an annual increase in public spending in the health sector. In 2020, an increase of 9.5 % was set compared to 2019. The funds are aimed at increasing the volume and scope of clinical pathways and activities related to the prevention and prophylaxis of socially significant diseases, which are the most common cause of death or permanent incapacity for work and injuries.

Social services in Bulgaria, including LTC services, are decentralised and are managed by the mayors of the respective municipalities. Municipalities are responsible for the provision of social services that are financed by the state budget or the municipal budget. Among the main responsibilities of the municipalities mayors are implementing the municipal policy in social services in accordance with the decisions of the municipal council; analysing the needs for social services in the municipalities; proposing to the municipal council the organisation of social services that are financed by the state budget or the municipal budget; managing the provision of social services that are financed by the state budget or the municipal budget in the municipality; being responsible for compliance with the quality standards for social services; controlling and monitoring the social services that are provided in the municipality, monitoring the lawful spending of funds from the state budget and the municipal budget for the financing of social services, etc. Organisations specifically created by the municipality for the provision of social services and private providers may provide social services after having been granted a licence by the Executive Director of the Agency for Quality of Social Services. Social service providers are monitored by the Agency for the Quality of Social Services, established through the Act.

[61] The Social Services Act (SSA) defines social services as 'activities aimed at supporting individuals in: prevention and/or overcoming of social exclusion; exercising rights; improving the quality of life. Social services shall be based on social work, an individual approach and individual needs assessments'.

***Box 1 Recent reform***

*In the context of the current reform, in March 2019, the Social Services Act was adopted by the National Assembly and came into force on 1 July 2020. The main objective is to improve the regulatory framework in social services, with a view to improving the planning, management, financing, quality, effectiveness and monitoring of the social services. The Law establishes a new Agency for the Quality of Social Services at the Ministry of Labour and Social Policy. There are two extremely important deadlines in the Transitional and Final Provisions of the Act: the final closure of all medical and social care homes for children (by 2021) and of all homes for adults with disabilities (by 2035).*

In social services there is an annual increase in the funds for social services, state delegated activities. In 2020 the increase is by BGN 30 million (approximately EUR 15 million) and the total amount is over BGN 290 million. To address the challenges due to the COVID-19 crisis the state budget was provided with additional financial resources of BGN 15 million to increase the standards for financing social services, activities delegated by the state. However, some challenges have been reported, related to the mechanism for their financing and the possibilities for the correct allocation of the available resource. Those challenges are addressed in SSA. According to this law, ensures closer adherence to standards for social services, finance by the state are regulated, and determined depending on the type of social service regarding the groups of activities, the group of users, quality standards, etc. Complementary financial standards for social services are also being introduced.

## 1.3 Social protection provisions

The three main risks for older people (aged 65 and above) are higher poverty rates, single households and poor health.[62] There are social assistance benefits and disability benefits but no LTC benefits as such. Financial support for different disadvantaged groups is provided on different legal grounds and under different conditions. Social assistance benefits are resources provided in cash and/or in kind which supplement or substitute incomes up to an amount sufficient to meet basic needs or to meet incidental needs of the beneficiary persons and families. Bulgarian citizens, families and cohabitants who due to health, age, social and other reasons beyond their control cannot cover through their work or income from property, or with the help of people obliged to support them to meet their basic life needs, are entitled to social benefits. Social assistance benefits are monthly, target or lump-sum. They are granted following an assessment of the income of the person or the family; the applicant's property status; the applicant's marital status; the applicant's health status; their employment status or other established circumstances relating to the case. The monthly amount of the guaranteed minimum income, serving as a basis for determining the amount of social assistance benefits is determined by the Council of Ministers. The provision of such material support is carried out through better targeting of social benefits, applying a differentiated approach depending on the specific needs of the assisted people and families. Social benefits are granted on the

[62] World Bank, *Harmonising services for inclusive growth. Improving access to essential services for vulnerable groups in Bulgaria, Technical report, Social Protection and Jobs Global Practice Europe and Central Asia Region*, 2019, p. 17.

basis of an application-declaration submitted by the person in need or by a person authorised by them after assessment of all data and circumstances established by a social survey. For the period 1 January 2019 to 31 December 2019 a total of 31,004 persons and families were supported with social assistance benefits.[63]

Cash benefits and more particularly, disability benefits, are provided to pensioners with permanently-reduced working capacity and a degree of disability exceeding 90 %, who need constant attendance. They can receive a supplement to their pension amounting to 75 % of the social old-age pension (106 BGN in 2020), as regulated by the Social Security Code. In 2015, those supplements accounted for 27 % of all LTC benefits provided in the country. In Bulgaria, 10.2 % of dependants aged 65+ receive formal in-kind LTC services and 28.7 % receive cash-benefits for LTC.

In 2015, municipalities provided LTC support amounting to 206 million BGN (EUR 105 million), accounting for 67 % of overall spending on LTC social services (European Commission, 2019, p. 308). Most of the services were targeted at people with disabilities. They included in-kind benefits for accommodation, rehabilitation, assistance in carrying out daily tasks and home-help provided to sick or injured people to assist them with their daily tasks.

However, there is scope for improvement in the social benefits system. Its low generosity and progressivity, as well as gaps in coverage – particularly among the poorest - undermine its impact in reducing poverty and social exclusion. Furthermore, as argued by the World Bank, the system lacks effective mechanisms to avoid dependency, abuse and fraud[64], and to promote labour participation (World Bank, 2019).

## 1.4 Supply of services

LTC social services for older people and people with disabilities are provided in specialised institutions, community-based social services for residential care, and also as daily and consultative community-based social services, as well as home-based social services[65]. After the adoption of SSA, social services are no longer defined as places/facilities but as activities providing support and empowering people to live independently. Social services are generally available and specialised. Generally available are the following ones: providing information, counselling and training to exercise social rights and for the development of skills for a period of no more than two months; mobile preventive community work. Specialised social services are the services provided in the cases of: the occurrence of a particular risk to the person's life, health, quality of life or development; needed to meet a specific need of a particular group of people. Depending on the main groups of activities, the social services are the following types: information and counselling; advocacy and mediation; community work; therapy and rehabilitation; training for acquiring skills; support for acquiring occupational skills; day care; residential care; providing shelter; assistant support.

[63] https://asp.government.bg/bg/za-agentsiyata/misiya-i-tseli/otcheti-i-dokladi
[64] To be noted that the Social Assistance Act provides for control mechanisms.
[65] http://www.mlsp.government.bg/eng/community-based-social-services

Bulgaria is in the process of deinstitutionalising the LTC system, aiming at a higher provision of home and community care services.[66] The main target groups of LTC are people with disabilities and older people (65+).

As of December 2019, the number of all specialised institutions in Bulgaria was 161, with a capacity of 10,881 places. In 2019, 30 new community-based social services for adults, including residential care, with a total capacity of 506 places were created. By September 2020, the number of community-based social services facilities for the older people and people with disabilities was 511, with a total capacity of 9503 places. This is a marked increase since 2012, when 335 community-based social services facilities for the older people and people with disabilities were available, with a total capacity of 6887 places[67].

The transition from traditional residential care to community and home-based social services is mainly realised through an expansion of the range of services (provided in day care centres, social rehabilitation and integration centres, protected housing and family-type accommodation centres). Home-based social services (for example, delivering meals to people at home and providing care services, such as help with personal or domestic hygiene) and public canteens are local activities financed by the state, municipalities and the Social Protection Fund of the Ministry of Labour and Social Policy[68]. Until the end of 2019, home-based care (personal and social assistance) to older people, people with disabilities and people living alone with serious diseases was provided under the National Programme 'Assistants to people with disabilities'. Under this programme, the funding reached 8.9 million BGN in 2017 and it provided employment for 2450 previously unemployed people.

In March 2020 the National Programme 'Provision of Home Care' came into force, which successfully continued the National Programme 'Assistants to People with Disabilities'. The implementation of the programme was a response to the need to improve the quality of life of people with a 80 to 89.99 % degree of permanently reduced working capacity or type and degree of disability and in need of assistance, and people over 65 years of age unable to care for themselves, which are not certified by the relevant bodies of medical expertise, by providing personal care in a home environment, aimed at supporting their daily needs for self-care.

Home-based services are also provided by private providers, as well as under different programmes, funded by the state or the European Social Fund. With regard to improving access to services at home, for the first time assistant support is regulated by the SSA as a key policy priority at national level. According to the law, assistant support is provided to people above working age who are unable to look after themselves and do not have a degree of reduced working capacity assessed in accordance with the relevant procedure or to children with permanent disabilities and adults with permanent disabilities in need of assistance who

[66] For the implementation of the process for deinstitutionalisation of care for older people and people with disabilities, in the SSA is foreseen that all specialised institutions for people with disabilities shall be closed by 1 January 2035 and that the existing homes for older people shall be reformed by 1 January 2025, in order to the meet quality standards.
[67] Social Assistance Agency, *Annual activity report for 2019*, (in Bulgarian) http://asp.government.bg/bg/za-agentsiyata/misiya-i-tseli/otcheti-i-dokladi.
[68] https://ec.europa.eu/social/main.jsp?catId=1103 and intPageId=4440 and langId=en

do not receive home care assistance under another law. This ensures access to this service for a certain group of vulnerable people, such as older people over 65 with limitations or an inability to look after themselves. The municipality undertakes to organise the provision of assistant support in such a way as to allow the comprehensive provision of the different types of social services at home[69].

There is a further development of the model for services provided at home (personal assistants, social assistants, domestic assistants, domestic social patronage, public canteens). According to the technical report by the World Bank, existing social services have not been developed systematically, and, in some cases, some municipalities and settlements are unable to provide adequate support (World Bank, 2019). This challenge is addressed in the SSA through regulation of the provision of assistant support.

Traditionally, LTC for older people is provided as informal care by family members.[70] There is little information about the number of people providing informal care. However, there is little doubt that the overwhelming bulk of LTC is provided by informal carers in families (European Commission, 2019, p. 310).

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Regarding access to LTC, the share of the population 65+ receiving care in an institution, as of 2019, was 0.5 % and the share of the population 65+ receiving care at home was 0.6 %. However, the share of the population 65+ receiving LTC cash benefits in 2019 was 3.1 %. The share of the population 65+ who used home care services for personal needs in the preceding 12 months to 2019 was 4.4 % in total – 5.1 % women and 3.4 % men. This percentage remains low. The share of households in need of LTC not using professional homecare services because such services are not available in 2016 was 13.3 %.[71] On the one hand, low shares of coverage may indicate a situation of under-provision of LTC services. On the other hand, higher coverage rates may imply an increased fiscal pressure on government budgets, possibly calling for greater need of policy reform. In addition, there is a striking and alarming difference in the share of households in need of LTC not using professional homecare services for financial reasons in 2016.[72] The figure is 65.1 % and is representative of the financial situation of ageing people in Bulgaria and their access to LTC. In comparison, the EU average is 35.7 %.[73] Regarding LTC beds per 100,000 inhabitants, there has been a decrease, resulting in 30.8 in 2017 compared to 43.7 in 2014, which is probably due to the move towards independent living.

[69] In 2021 assistant support will be provided by the municipalities with state funding and this type of social service will be entirely free for the recipients.
[70] Ludmila Mincheva and Galina Kanazireva, *The long-term care system for the elderly in Bulgaria.* http://www.ancien-longtermcare.eu/sites/default/files/ENEPRI %20RR %20no %2071 %20_Ancien_ %20Bulgaria.pdf, 2010.
[71] EU-SILC data 2016: ils_ats15.
[72] Idem.
[73] Idem.

In Bulgaria, the geographic coverage of LTC social services and other services is uneven across districts, partly reflecting differences in population. Generally, most social services with larger capacity are located in administrative centres where the population is higher although some large institutions for people with disabilities are situated in small settlements. While all types of social services have expanded in the past few years, there remain needs that are unmet. In 2008, the number of registered beneficiaries waiting for services equalled approximately one third of existing capacity. According to the action plan for LTC for the period 2018–2021, there were 3600 on waiting lists vs. 11,000 placed in specialised institutions.

Regarding accessibility, the SSA gives priority to support in the home environment and in the community. The use of social services for residential care is allowed only if the possibilities for supporting people through social services at home and in the community have been exhausted. Anyone who needs support for the prevention and/or to overcome social exclusion, exercising rights or improving their quality of life, regardless of age, health condition, education, income, social and property status, is entitled to social services. Social services are provided upon the request of the potential beneficiary and after a preliminary assessment of the need for social services and the establishment of an individual needs assessment and an individual support plan. Everyone has the right to use the generally available social services without a preliminary needs assessment. Social services can be used: short-term - for a period of up to six months; medium-term - for a period of up to one year; long-term - for a period of between one and three years. As the SSA came into force on 1 July 2020, no data is available yet on how the objectives and ambitions of the law as described above translate into practice.

Regarding affordability, it should be stated that the fees for formal institutional LTC care can be significant. For example, a person who is enrolled in a public facility for institutionalised older care needs to transfer up to 80 % of their retirement income, but not higher than the actual monthly expenditure for the service provided. Fees for social services which are financed by the state budget are fixed by a Tariff of Social Services Fees endorsed by the Council of Ministers. According to the tariff, the amount of the social service fee is determined as a percentage of the person's income, depending on the type of social service. For each type of social service there is a certain percentage of the persons' income to be paid. People with no income or savings, people living in shelters and in crisis centres, as well as those who have transferred real estate property to the state or to a municipality with the purpose of developing social services, are exempted from paying fees for social services.[74] The payment for social services provided by private providers is made on a negotiated basis when the social services do not constitute activities delegated by the State (European Commission, 2019, p. 309). There is no information available for out-of-pocket payments.

With the SSA, a new mechanism for determining fees is set out. The annual fee for using each social services financed from the state budget is formed as a percentage of the amount of the annual standard for activity delegated by the state for the respective social service.

[74] An implementing act is under preparation that will affect the payment of fees.

According to SSA, there are a large range of cases where people are exempted from paying fees. The cases in which people are not required to pay the full amount for using social services that are financed by the state budget are laid down in the regulations for implementation of the Act. The fees for using social services that are provided by the municipality and are not financed by the state budget is determined by the municipal council in accordance with the Local Taxes and Fees Act. The fees for social services financed by private providers are fixed by the provider.

## 2.2 Quality

The action plan for the implementation of the National Strategy for Long-Term Care for the period 2018-2021 established in 2018, aims to address some of the challenges identified in the strategic document for LTC in Bulgaria[75], such as the development of quality standards for social services for older people and people with disabilities. However, implementation of these measures is yet to be seen and evaluated. There is ongoing implementation of the 'New Standards for Social Services' project; an important activity involving the development of quality standards with objective and measurable criteria and indicators and a monitoring and control system of the services.

For the provision of social services there are certain quality standards that provider should met. The ongoing reform establishes the adoption of new and more precise standards for the quality of social services, as well as the adoption of a special ordinance on the quality of social services which is under preparation. The standards are for the organisation and management, for the qualification and professional development of employees and for the efficiency of the service in meeting the needs of person in care.

In addition, the SSA establishes a new Agency for the Quality of Social Services at the Ministry of Labour and Social Policy. The new structure will monitor how municipalities and private providers are delivering social services and spending state funds. Its objective is to verify compliance with the rights of users of social services, monitor national performance and license all private social services providers. It will create common standards for providers but, at the same time, will give them the freedom to develop their own practices and relationships between professionals, children and parents, since the system was previously highly restricted by methodological guidelines. The integrated approach provides for improved and facilitated access to the labour market and to social, health and education services. The new law also aims to improve the skills and wages of social service workers.[76]

However, the system remains overregulated and fragmented, and is supported by a management scheme that lacks incentives for coordination or integration. It has substantial quantity and quality gaps in coverage (World Bank, 2019).

To address the challenges mentioned above, the integrated approach in the provision of long-term care services is set out in the SSA. Integrated health and social services can be provided

[75] National Long-term care strategy of Bulgaria, 2014, http://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG and Id=882.

[76] Standards for remuneration of employees performing activities for the provision of social services, which are financed from the state budget are determined in an ordinance.

for permanently disabled children or adults; people with chronic diseases; people above working age who are unable to look after themselves. Integrated health and social services shall be services for specialised support to individuals through activities in health care and social services that are provided within the framework of common organisation and support. Support through integrated health and social services is provided by medical professionals and by professionals who provide social services. The providers should meet quality standards for integrated health and social services. Control of compliance with the quality standards should be exercised by the Agency for Quality of Social Services with the participation of representatives of the regional health inspectorate.

## 2.3 Employment (workforce and informal carers)

In 2016, the number of LTC workers providing informal care was 1 per 100 individuals aged 65+, 87.7 % of whom were women. The share of the population providing informal care was 6.1 %, among which the share of informal carers providing more than 20 hours of care per week was 36.6 %. In addition, as LTC workers follow the common migration routes between lower and higher income countries and Bulgaria is stated as one of the 20 countries which are primarily sources of outflow and new immigrants to the OECD (EU MS included) in 2015.[77]

There were so far no specific efforts to address the need to recruit, motivate and maintain a competent workforce.[78] There are some recruitment programmes targeting specific groups, however they do not typically consider a job in LTC – young, men, the retired, etc. as well as the challenge related to the high turnover of social workers, nurses and health specialists going abroad, etc. There is no established information system collecting data on formal carers providing LTC. There is even less information about the number of people providing informal care. Since 2012, training for the professionalisation of care has been conducted under various schemes under OP 'Human Resources Development' (OP HRD). Though well-intended, these efforts lack a comprehensive and systematic approach. There is also a lack of information about any initiatives for skills validation for informal learners to assist them in becoming LTC professionals. In Bulgaria, there is no high education degree requirement for being employed as a personal care worker. There is only a requirement of a technical degree after high-school for becoming a nurse in the LTC sector. Personal care workers, who have lower education levels than nurses, particularly need to receive training. Bulgaria is not one of the countries that require that these professionals follow training in older care (OECD, 2020). In addition, in Bulgaria there is no governmental sponsoring of LTC education, and financial support is mostly given by a European Commission programme: the European Social Fund (ESF) Operational Programme for Human Development. Under the operation 'Capacity building of employees in the field of child protection, social services and social assistance', implemented within the programme in 2018 and 2019, specialised training for workers in social services was conducted. The purpose of the training is to increase the capacity and professional competence of employees to provide social services and improve

[77] OECD, 'Who Cares? Attracting and Retaining Care Workers for the Elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en.
[78] Bogdanov, G. and Georgieva, L., *ESPN Thematic Report on Challenges in long-term care for Bulgaria*, European Social Policy Network (ESPN), European Commission, Brussels, 2018.

their practical skills in accordance with the individual needs of users. A total of 6720 people from 1358 social services have received training.

To address challenges mentioned above, the SSA introduced the right to supervision, mentoring and induction and further training for employees, providing social services. The employees who carry out activities relating to the provision of social services are entitled to induction training and further training which is mandatory for them. Training is provided in accordance with a programme for induction and further training of staff developed by the provider. For employees who carry out social services activities for the first time, the social service provider is obliged to appoint mentors to assist them for a period of six months from the date of their appointment. They should participate in the activities in exchange for experience and familiarising with good practices arranged for them. Also, they have the right to regular supervision during the course of their work. In an ordinance on the quality of social services, which being prepared, the minimum requirements for the number and qualification of the necessary staff who carry out different types of social services activity will be determined as well as the obligations of social services providers to ensure the professional and career development of their employees.

Financial support to informal carers was available until the end of 2019 through a dedicated programme mentioned above - National Programme 'Assistants to people with disabilities'.

Since January 2019, the Personal Assistance Act, which regulates the Personal Assistance Mechanism, has been in force. The provision of personal assistance began in September 2019. According to the Act, the assistants selected by the user, may be family members of the disabled person, part of the extended family circle, or those outside. After an interview and approval by the municipality, the assistant must be added to the list of assistants maintained by them. Assistants can receive training by the municipalities but it is not mandatory. The user of the personal assistance participates in the negotiation, management and control of the type and duration of the work performed by the assistant. Although the purpose of the mechanism is to support people with disabilities, it can also support informal family members.

Informal carers can receive support in accordance with the Social services act. The SSA introduced entirely free support and training services for family members who provide informal care at home for people with permanent disabilities and for people with disabilities over the working age who are unable to look after themselves. The law also establishes the right to respite care for families and people caring for adults with permanent disabilities and for older people in need of care at home. In this way, the state provides an additional opportunity to support those who care for their older relatives. As mentioned, it is too early to assess the effectiveness of these provisions.

However, as observed by the World Bank, case management and the role of social workers - both at the core of service provision – remain fragmented and limited to certain groups such as children at risk and the registered unemployed and for certain services, leaving other vulnerable groups such as people with disabilities or those in need of LTC without support (World bank 2019).

## 2.4 Financial sustainability

In Bulgaria, public spending on LTC, was 0.3 % of GDP in 2019, far below the EU average of 1.7 % of GDP. According to the 2021 Ageing Report[79], in 2019, 69.2 % of this expenditure was spent on in-kind benefits (EU: 73.6 %), while 30.8 % was provided via cash-benefits (EU: 26.4 %) (European Commission, 2019).

According to the 2021 Ageing Report, projected public expenditure on LTC as a % of GDP for Bulgaria will rise from 0.3 % in 2019 to 0.4 % by 2050.[80]

Under the implementation of the previously mentioned project 'New Standards for Social Services', there is an aim to develop up-to-date financing and financial models for pricing the provision of social services, including for LTC services, as well as a model for financing the integrated cross-sectoral services.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

People with disabilities, as another group in need of care, are supported financially under the Law on People with Disabilities, in force since January 2019, the Law on Personal Assistance, the ordinance on inclusion in the mechanism for personal assistance and under other legislative acts. Both laws expand the scope of eligible people with disabilities by including overcoming social isolation, to receive adequate care in a family environment, as well as to guarantee access to rehabilitation and appropriate and timely medical care, etc. People with disabilities receive in-kind rehabilitation services accounting for 0.5 % of public expenditure on LTC services. They receive allowances and invalidity pensions due to general illness and/or supplement for external care in the event of more than a 90 % degree of disability.

As already mentioned, cash benefits are provided to pensioners with permanently reduced working capacity and a degree of disability exceeding 90 %, who c need constant attendance.

In addition, under the Law on Family Allowances, all family allowances are provided to children with disabilities, regardless of family income. As of January 2017, a new monthly allowance for raising a child with a permanent disability was introduced with amendments to the Law on Family Allowances, affecting more than 26,000 disabled children. The allowance is differentiated according to the degree of the disability or the degree of the reduced capacity of the child and ranges from 350 BGN (EUR 178.5) to 930 BGN (EUR 474) (European Commission, 2019, p. 308).

# 3 REFORM OBJECTIVES AND TRENDS

At the beginning of 2014, the Council of Ministers adopted a National Strategy on long-term care[81], followed by the current plan for the Implementation of the National Strategy, covering

[79] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.
[80] Idem

the period 2018-2021, adopted in January 2018[82]. This plan envisages the setup of 100 new community-based social services for 2140 users as well as the development of cross-sectorial services, including at home such as patronage care. Patronage care will be developed, aimed at improving the quality of life and opportunities for social inclusion for older people and people with disabilities, by providing a network of integrated health-social and social services at home and building appropriate capacity to provide them), for older people and those with disabilities dependent on care. Over 30,000 people will be supported through patronage care and assistant services. The main measures in the Action Plan are as follows: providing support in at home and in the community for people with disabilities and older people dependent on care; providing quality community-based social services for people living in specialised institutions with poor living conditions and quality of care and closing of institutions; enhancing the effectiveness of the long-term care system; building the necessary infrastructure for providing social and integrated health and social services for people with disabilities and older people dependent on care (European Commission, 2019, p. 313).

Social services' reform, including long-term care, is also supported by the implementation of the 'New Standards for Social Services' project which was introduced in 2016. It aims at improving the accessibility, effectiveness and quality of social services, as well as the independent living for children and adults who need care, including people with disabilities, by developing up-to-date quality standards and financing in line with the needs of the recipients. The implementation of the ongoing project activities will also assist the overall reform in the social services sector.

As was mention above, a comprehensive reform in the social services sector is underway as part of the efforts to provide an entirely new model of providing accessible, qualitative, effective and integrated social services to more adequately meet the needs of vulnerable people with the implementation of the SSA in 2020. According to the Bulgarian Centre for Not-for-Profit Law (BCNL), several basic concepts in the SSA, create high expectations of a real and irreversible reform that will lead to better-quality services for direct recipients. As to positive trends triggered by the legislation, the BCNL emphasises the clear statement that only quality services will be developed and funded. All private providers will be licensed under the SSA, and even municipal services will have to meet the same high-quality standards; if the standards are not met, funding will be phased out. Currently, there are municipal and private/NGO providers of services for adults, but they are not licensed, just registered. Under the Act, private services for adults will also be licensed, and all services will be monitored by the new Agency for the Quality of Social Services. In addition, a crucial part of the imposed legislation is the focus on the individual needs of every person; this is

[81] National Long-term care strategy of Bulgaria, 2014, http://www.strategy.bg/StrategicDocuments/View.aspx?lang=bg-BG and Id=882

[82] Action Plan for the Implementation of the LTC Strategy for the period 2018 – 2021, https://mlsp.government.bg/ckfinder/userfiles/files/politiki/socialni %20uslugi/deinstitucionalizaciq %20na %20grijata %20za %20vuzrastni %20hora %20i %20hora %20s %20uvrejdaniq/Plan_LTC.pdf.

something entirely new as a philosophy and a basis for further quality development of services.[83]

During the COVID-19 pandemic, there was a high level of COVID cases amongst older people in residential homes and the workforce in those homes. In response to the outbreak, the government relocated the people in LTC from specific residential homes with proven positive COVID-19 tests to hospitals and other residential homes around the country[84]. To determine the presence of COVID-19 infections, up until the end of August 2020, PCR tests were performed on 9245 people in residential care and 7120 employees. As of 11 August 2020, the total number of infected people in long-term care was 186 and 70 employees. 22 people in specialised institutions had died.[85]

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

To improve the governance framework, the government should strategically integrate medical and social services via a legal framework and establish information platforms available for LTC users and providers. On matters related to the improvement of the financing arrangements, the recommendations for the state would be to face the increased LTC costs in the future e.g. to foster pre-funding elements, which implies setting aside some funds to pay for future obligations and explore the potential of private LTC insurance as a supplementary financing tool. Regarding the provision of adequate levels of care to those in need, there should be a focus on the provision of targeted benefits to those with highest LTC needs and the risk of poverty of recipients and informal carers should be minimised. In addition, independent living should be encouraged by providing effective home care, tele-care and information to recipients, as well as improving the home and general living environment. On ensuring availability of formal carers, there should be an improvement in recruitment efforts. Regarding the support of family carers, efforts should be put into ensuring that women are not encouraged to withdraw from the labour market for caring reasons. Moreover, focus should be put on prevention, promoting healthy ageing and preventing the physical and mental deterioration of people with chronic care should be of highest priority together with identification of risk groups and the detection of morbidity patterns earlier.[86]

As the Institute for the Market Economy states[87], imbalances in the provision of services at local level exist and it needs to be clarified whether those imbalances are an issue or are a natural result of the difference in the need for such services locally. Hence, it is considered as unrealistic to target full territorial coverage of social services as imposed by the SSA.

[83] Bulgarian Centre for Non-for-Profit Law, *Did you read the NEW Social Services Act*, 2019. http://bcnl.org/en/news/did-you-read-the-new-social-services-act-.html.
[84] Darik news, *Elderly people with coronavirus are being taken out of retirement homes*. https://dariknews.bg/novini/bylgariia/izvezhdat-vyzrastnite-hora-s-koronavirus-ot-starcheskiia-dom-v-kula-video-2224548
[85] According to the Social Assistance Agency.
[86]European Commission, 'Joint Report on Health Care and Long-Term Care Systems and Fiscal Sustainability Volume 2 – Country Documents 2019 Update', *Institutional Paper 105,* Publications Office of the European Union, Luxembourg, 2019. https://ec.europa.eu/info/sites/info/files/economy-finance/ip105_en.pdf.
[87] Institute for Market Economy, *The new law on social services: step forward, step away or back there?*, 2019. Available (in Bulgarian) https://ime.bg/bg/articles/noviyat-zakon-za-socialnite-uslugi-napred-vstrani-ili-pak-tam/.

Therefore, more attention should be put into planning the scale of services and their cost, to achieve adequate availability and quality of service for all in every region.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 7.5 | 7.0 | 6.5 | 5.7 |
| Old-age dependency ratio, 2019 | | 25.8 | 33.2 | 39.0 | 55.0 |
| Population 65+ (in millions), 2019 | Total | 1.3 | 1.5 | 1.6 | 1.7 |
| | Women | 0.8 | 0.9 | 0.9 | 1.0 |
| | Men | 0.5 | 0.6 | 0.6 | 0.8 |
| Share of 65+ in population (%), 2019 | | 17.8 | 21.3 | 24.3 | 30.7 |
| Share of 75+ in population (%), 2019 | | 7.6 | 8.8 | 11.8 | 16.0 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 15.6* | 16.3 | | |
| | Women | 17.1* | 18.1 | 19.6 | 22.3 |
| | Men | 13.8* | 14.2 | 15.9 | 18.8 |
| Healthy life years at the age of 65, 2018 | Total | 9.4* | 9.8 | | |
| | Women | 9.9* | 10.2 | | |
| | Men | 8.9* | 9.2 | | |

*data for 2010

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 258.5 | 264.1 | 268.1 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 162.3 | 177.4 | 205.2 |
| | Women | | 104.0 | 114.7 | 125.8 |
| | Men | | 58.3 | 62.7 | 79.3 |
| Share of potential dependants in total population (%), 2019 | | | 3.7 | 4.1 | 4.8 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 10.8 | 11.3 | 11.8 |
| Share of population 65+ in need of LTC** (%), 2019* | | 35.4 | 27.9 | | |

*data not available for all Member States;
**at least one severe difficulty in ADLs and/or IADLs

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 0.5 | 0.5 | 0.5 |
| Share of population 65+ receiving care at home (%), 2019 | | | 0.6 | 0.7 | 0.7 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 3.1 | 3.3 | 3.4 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 10.2 | 10.2 | 10.2 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 28.7 | 28.9 | 29.1 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 75.2 | 67.5 | | |
| | Women | 77.9 | 69.4 | | |
| | Men | 69.8 | 63.4 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 7.4 | 4.4 | | |
| | Women | 7.8 | 5.1 | | |
| | Men | 6.7 | 3.4 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 65.1 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 13.3 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 43.7 | 30.8 | | |

*data not available for all Member States;
**at least one severe difficulty in ADLs and/or IADLs

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 1.4 | 1.0 | | |
| | % Women | | 87.7 | | |
| Share of population providing informal care (%), 2016 | Total | | 6.1 | | |
| | Women | | 6.9 | | |
| | Men | | 5.3 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 36.6 | | |
| | Women | | 43.2 | | |
| | Men | | 27.2 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.4 | 0.3 | 0.3 | 0.4 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.4 | 0.3 | 0.4 | 0.8 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 31.3 | 22.6 | 23.7 | 25.2 |
| Public spending on home care as % of total LTC public spending, 2019 | 68.8 | 46.6 | 44.6 | 43.9 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 0.0 | 30.8 | 31.7 | 30.9 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# CZECH REPUBLIC

***Highlights***

- Demographic trends suggest a significant increase in the need for long-term care services. Extra capacity will be needed in the next 10-15 years to prevent a decline in current standards of accessibility. A need for increased expenditure can be expected too.
- There is an insufficiently developed supply of formal home care in the country. The services do not meet the needs of dependent people and informal carers. Home care and respite care should be strengthened.
- Residential care suffers from insufficient bed capacity and consequently limited accessibility. The social services system is not ready for the effects of population ageing.
- There were no reforms during the period under scrutiny. There are four areas presenting significant challenges: governance, capacity building and investment, quality assurance, and home-based service support, both formal and informal.

# 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM

## 1.1 Demographic trends

The Czech Republic is predicted to have a fairly constant population size in the next 30-50 years. At the same time, it is a country with an ageing population along with the other EU countries. Population ageing is linked to increasing numbers of long-term care (LTC) beneficiaries and, at the same time, to a decline in workforce numbers. The old-age dependency ratio increased from 20.6 % in 2008 to 30.4 % in 2019 and is projected to be 35.2 % in 2030 and 49.8 % in 2050.[88] Data on the old-age dependency ratio closely follows the pattern within the EU as a whole. A projection from November 2019, made by the Czech Statistical Office[89], is consistent with this data and extends the time series beyond 2050. Similarly, a recent development and projection of the share of the population aged 65+ and the share of the population aged 75+ suggest a parallel development in the Czech Republic and in the EU as a whole. The share of the population aged 65+ rose from 14.6 % in 2008 to 19.6 % in 2019 and will almost double by 2050 (22.0 % in 2030 and 28.2 % in 2050). The proportion of the population aged 75+ will grow relatively faster and will almost double between 2019 (7.7 %) and 2050 (14.5 %). The age structure in regions follows a similar

[88] All data used in the text come from Section 5 'Background statistics' unless explicitly stated otherwise
[89] Czech Statistical Office (CZSO), *Projekce obyvatelstva v krajích ČR - do roku 2070,* 2019a [Population projections in regions of the Czech Republic - until 2070]. https://bit.ly/3c841vU.

pattern (CZSO, 2019b)[90]. Regional differences could increase slightly as larger regional centres with better infrastructure may attract more investment and higher labour demand. For example, in the Prague region, the share of the population aged 65+ is expected to be 18.8 % in 2030 and 24.0 % in 2050, whereas in the Zlín region it will be 24.5 % in 2030 and 32.1 % in 2050 (CZSO, 2019a).

The expected evolution of the share of the population aged 65+ (and the old-age dependency ratio) suggests that we can anticipate an increasing demand for LTC-related services in the Czech Republic. The share of the population aged 65+ in need of LTC, defined as having at least one severe difficulty in personal care and/or household activities, was 30.5 % in 2019. A mild decrease in healthy life years at 65 (8.8 for women in 2010 compared with 8.5 in 2018, and 8.5 compared with 8.1 for men in the respective years) do not support any optimistic prediction concerning lowering the share of the population aged 65+ in need of LTC.

The total number of potential dependants[91] will grow from 706,700 (representing 6.6 % of the total population) in 2019 to 806,700 (7.5 %) in 2030 and 861,200 (8.2 %) in 2050 (see Section 5 'Background statistics'). The average share of potential dependants in the EU's population was already 7.0 % in 2019, expected to increase to 8.8 % in 2050. The trend towards population ageing began later in the Czech Republic than in the EU countries to the west of the Czech Republic. Therefore, the population in the Czech Republic is now ageing faster than in older EU Member States. Consequently, the share of potential dependants is increasing more quickly.

## 1.2 Governance and financial arrangements

The development of long-term care has been carried out in a fragmented fashion in the Czech Republic, with responsibility strictly divided between the healthcare sector and the social care sector.[92] Under the public health insurance system, as introduced in 1993, providers of healthcare services and social services had to be mutually distinct entities. Residential social care providers' entitlement to provide some health care (mainly nursing care) covered by the public insurance scheme was re-established in 2006. However, the governance of long-term care, as well as palliative, health and social care, remains an issue. In 2008, the National Plan of Action on Ageing 2008-2012 declared that the division of responsibilities and funding increased the risk of fragmentation and insufficient coordination of services, poor transparency of the system for clients as well as providers, low flexibility of services and unclear responsibility for achieving results[93]. Unfortunately, this is still the case. Separate

[90] Czech Statistical Office (CZSO), *Proměny věkového složení obyvatelstva ČR – 2001-2050* [Changes in age structure of the population in the CR], 2019b. Available in Czech only. https://www.czso.cz/csu/czso/promeny-vekoveho-slozeni-obyvatelstva-cr-2001-2050.

[91] The 2021 Ageing Report calculates potential dependants as people with severe activity limitations from EU-SILC plus they add the number of people living in institutions.

[92] Most statistics do not treat LTC as a distinct area consisting of social care and health care. The statistical yearbook of the Ministry of Labour and Social Affairs (MLSA) covers LTC services as part of a broader system of social services dealing with other target groups and does not include services provided at health facilities. Aggregate numbers of staff, wages and expenditure are either difficult or impossible to relate to LTC only.

[93] MLSA (Ministry of Labour and Social Affairs CR), *Národní program přípravy na stárnutí na období let 2008 až 2012 (Kvalita života ve stáří)* [National Plan of Action on Ageing 2008-2012 (Quality of Life in Old Age)], 2008. https://www.mpsv.cz/web/cz/narodni-program-pripravy-na-starnuti-na-obdobi-let-2008-az-2012-kvalita-zivota-ve-stari-.

legislation regulates each of the sectors; they have a different funding scheme as well as governance. Institutional governance of LTC is a vertically fragmented, plural system, with responsibilities distributed between different institutional tiers: the state, the regions and municipalities. Regions play an essential role in planning and coordinating capacities, both regions and municipalities serve as major founders of public institutions providing social services.

Family members and friends provide most care. There is not a legal obligation for children to care for their parents but there is a maintenance obligation (§ 915 of the Civil Code).

Formal carers in social services can be registered or unregistered. If registered, they are bound by maximum administrative prices. If a person is unregistered, then free pricing of services applies, with the cost to be fully covered by private payments (EC, 2019)[94].

There is no explicit and separate long-term care insurance scheme in the Czech Republic. Multi-source funding is a key funding concept. Clients' fees represent the main funding resource for social services. Other sources consist of subsidies and grants provided by the Ministry of Labour and Social Affairs (MLSA) and flowing into regional governments' budgets. Some services, such as social prevention or rehabilitation, are provided without private co-payments. As for residential care, recipient's income (up to 85 %) can be used to cover accommodation and food costs for residential care. Reimbursement of other social services costs is limited by the recipient's care allowance. Any remaining costs have to be covered privately, either by the recipient or their family (EC, 2019).

Health insurance funds are by far the most important resource for long-term health services – they cover almost all the costs. (A detailed analysis of spending is presented in section 2.4.) The law on social services[95] handed over a substantial share of public funds to the recipients of social services, in the form of care allowance. The allowance is scaled into four levels, according to the recipient's degree of dependency on support (for details and other cash benefits, see section 1.3).

## 1.3 Social protection provisions

Social protection measures differ according to the sector of LTC. Health and social services are addressed separately.

There is universal free access to LTC health services for any resident. The level of a cap on drug co-payments is age-based. Children and people aged 65-70 are eligible for a reduced cap of one-fifth of the regular limit. People over 70 as well as some people with disabilities can pay only half of the reduced level.

There is a set of cash allowances for people in need of LTC social services (see below).

Eligibility for the care allowance is based on an assessment of the level of dependency on care. The care allowance is provided to people who, due to their long-term unfavourable

[94] European Commission, *Joint Report on Health Care and Long-Term Care Systems and Fiscal Sustainability, Country Documents – 2019 Update*, 2019. https://bit.ly/36MR897
[95] Act No 108/2006 Coll., https://bit.ly/3eB3800

health condition, are dependent on another person's assistance when dealing with basic living needs. The criteria for granting a specific allowance level are specified in the law on social services. The care allowance is divided into four levels, according to the recipient's degree of dependency on support. The highest level of dependency entitles the recipient to a care allowance of CZK 13,200 or CZK 19,200, it is around half of the average salary and slightly above the average pension in the country. It is worth noting that this is not necessarily enough – for instance, the amount of benefit for people with heavy dependency (level 3) who do not use residential services (CZK 12,800/EUR 497 monthly) can cover approximately 3.5 hours of care per day.[96] Applications for care allowance are processed by regional labour offices. Their officers conduct an on-the-spot investigation of the ability of applicants to live independently in their natural social environment. Subsequently, the regional office sends a request to the relevant district social security administration to establish the degree of dependence.

There are also specific allowances guaranteed to people with disabilities (see Act No. 329/2011 Coll.). They include mobility allowance and special-aid allowance.[97]

The Czech Republic fits the traditional model where LTC is largely considered a 'family business' and family members and friends provide most non-medical care. A long-term attendance allowance was introduced in 2018 to address the financial situation of family members who provide care for their dependent relatives (for details, see section 3).

The state pays health insurance premiums, through the state budget, on behalf of those who are dependent on assistance from others at level 2 (medium), level 3 (heavy) and level 4 (full) dependency, and on behalf of those caring for these people, including people caring for children younger than ten years old who are dependent on assistance from others at level 1 (mild) dependency.

## 1.4 Supply of services

According to the 2015 National Strategy for Social Services Development, just 15 % of individuals in need of LTC are clients of residential care in healthcare or social care facilities. Most long-term care is provided as informal care by people close to those in need of care (MLSA, 2015)[98]. The share of the population aged 65+ receiving residential care was 4.2 % in 2019 compared with 4.5 % that received care at home (See Section 5 'Background statistics'). Cash benefits mentioned in the previous section 1.3 are intended to form a

[96] Low-income families with children have higher support. A monthly increase of CZK 2000/EUR 74 of care allowance is provided to a dependent child under 18 or to a parent of a dependent child if their income is lower than two times the living minimum of the family.

[97] **Mobility allowance** is designated for persons with disabilities who use paid transportation repeatedly during a month. The amount of the benefit is CZK 550/EUR 22 per month. A person with a long-term severe disability of support and motion apparatus, blind or deaf (in the case of aid 'vehicle' or 'special restraint systems' also with serious mental disability) is entitled to a **special-aid allowance** to purchase the needed aid (device) not covered by the health insurance system, e.g. aids enabling self-reliance, working activities, education, social contacts, including a motor vehicle, adaptation of a motor vehicle, construction works adjusting a home, accessing a home(stairway lift and other arrangement. The amount of the allowance reflects the price of the aid and income conditions of the applicant.

[98] MLSA (Ministry of Labour and Social Affairs CR), *Národní strategie rozvoje sociálních služeb na období 2016-2025* [National Strategy for Social Services Development in 2016-2025], 2015. https://bit.ly/2Mnwe6N

significant source of funding these services. The share of the population aged 65+ receiving LTC cash benefits was 12.0 % in 2019.

Residential facilities represent the most complex form of social services for seniors. The Social Services Act defines three main types: homes for the older people, special-regime homes (for older people with reduced self-sufficiency and ageing diseases), and week-care centres[99]. Besides these, there are so-called boarding houses for older people (they operate on the basis of a rental relationship), residential homes (established by municipalities, not governed by the Social Services Act) and long-term care facilities (medical facilities).

At the end of 2019, there were 524 registered homes for older people in the Czech Republic with a capacity of 36,688 beds. Private and non-profit establishments (excl. church) account for 13 % of the total bed capacity. There were also 349 registered special-regime homes with 20,904 beds (with 39 % of the bed capacity in private and non-profit facilities). Regional and municipal facilities predominate, accounting for 80 % of the total number of beds in homes for older people and 58 % for special-regime homes.[100] There were 687.5 long-term care beds per 100,000 inhabitants in 2017, representing an increase of 3.8 % since 2008 (See Section 5 'Background statistics').

The total number of places in retirement homes has practically not changed since 2009 (ibid). The capacity of both homes for older people and special-regime homes is almost full in all regions and the MLSA statistics show more than 60,600 unsatisfied applications for places in homes for older people and 26,100 unsatisfied applications for places in special-regime homes at the end of 2019 (ibid). As applicants usually submit more than one application, it is not easy to assess the level of unmet demand. The association of social services providers estimates that there are roughly 20,000 waiting for a place. In view of demographic developments, the demand for places in residential facilities for older people will increase rapidly in the future.

The Czech Republic has an insufficiently developed supply of home social services (e.g. respite support, personal assistance, day-care homes, etc.). These services do not meet the needs of either carers or of dependent people. Respite support (provision of a short break from caring duties) and psychological support and counselling for carers are the services most lacking. Tomášková[101] published a survey mapping the usage of health and social services available to those who care for a dependent person. Her findings suggest a large gap of unmet needs.

Notwithstanding the importance of informal carers[102] (mostly family members and friends), LTC is also a significant segment of the labour market. The trade unions estimate that there

[99] Week-care centre [týdenní stacionář] is a residential social service, which is defined by the Social Services Act. It takes care of people who are cared for by their family on weekends and public holidays.
[100] https://www.mpsv.cz/web/cz/statisticka-rocenka-z-oblasti-prace-a-socialnich-veci
[101] Tomášková, V., *Sociální a zdravotní služby nejen pro osoby v neformální péči* [Social and health services not only for people in informal care], 2015. https://bit.ly/3cjyx5G
[102] According to a survey of MLSA there were about 305 thousand informal carers in 2018, i.e. carers that took care for dependent people receiving care allowance.

are overall roughly 100,000 employees in the social services sector[103]. Official MLSA statistics that cover public-sector employment report nearly 45,000 employees, including 24,000 social workers and 5000 nurses[104].

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

According to Hashiguchi and Llena-Nozal[105], even after receiving public support, out-of-pocket costs for formal home care can be very high for older people with severe needs. These contributions can put them at risk of poverty given that they still need to pay for basic costs of living, such as electricity and food. In the Czech Republic, out-of-pocket costs for home care take up more than half the median income of an older person. However, the share of households in need of LTC not using professional homecare services for financial reasons was less than half the EU's average in 2016 (16.1 % and 35.7 %, respectively). A shortage of available services (because of low capacities or spatial disparities) may serve as an intuitive explanation for such a paradox. However, the Eurostat indicator 'People using or not professional homecare services by reason'[106] does not seem to support this. In essence, the share of households in need of LTC not using professional homecare services because services were not available was only 3.7 % in 2016 (compared with the EU's rate of 9.7 %). A closer look into national data (CZSO, 2019c)[107] suggests that while by far the most frequently used social service – nursing care – has a proportion of unmet applications of 3.4 %, other services have a much higher proportion: personal assistance 18 % and respite care 15 %[108] in 2018.

Regarding residential care, as we mentioned in section 1.4, insufficient bed capacity is the main challenge and the reason for limited access. As Horecký and Průša state (2019, p.13)[109], 'it is clear that the social services system is not ready for the effects of population ageing. (Heavy) dependency of providers on subsidies from the state budget prevents the necessary development of social services'. Czech social services capacities (mainly residential ones) are below the European average. The gap is getting more significant, as the country's response is

[103] Chválová, J. *Platy a počty zaměstnanců v sociálních službách v letech 2014 až 2016* [Salaries and Number of Employees in Social Services in 2014-2016], 2017. https://bit.ly/2MfBR71
[104] MLSA (Ministry of Labour and Social Affairs CR), *Statistická ročenka z oblasti práce a sociálních věcí 2016* [Statistical Yearbook of Labour and Social Affairs, 2016], 2017b. https://www.mpsv.cz/documents/20142/372765/Statisticka_rocenka_z_oblasti_prace_a_socialnich_veci_2016.pdf/f44dd756-9300-9a25-4fa8-3a7596cade4a
[105] Cravo Oliveira Hashiguchi, T. and Llena-Nozal, A., 'The effectiveness of social protection for long-term care in old age: Is social protection reducing the risk of poverty associated with care needs?', *OECD Health Working Papers* No 117, OECD Publishing, Paris, 2020. https://bit.ly/2ApYPFZ
[106] See Section 5 'Background statistics'.
[107] Czech Statistical Office (CZSO), *Vybrané ukazatele o sociálním zabezpečení za rok 2018* [Selected social security indicators, 2018] 2019c. https://bit.ly/3gCXrjY
[108] For the sake of simplicity, we assume only one application per household in need.
[109] Horecký, J., Průša, L., *Současná struktura služeb dlouhodobé péče a prognóza potřebnosti sociálních služeb 2019–2050*, 2019, p. 13. [Current structure of LTC services and a prognosis of the need for social services 2019-2050]. https://bit.ly/2Mk3Dj4

both insufficient and late (ibid). There is no realistic central plan of building up additional social services capacities for the older people.

## 2.2 Quality

Quality assurance processes differ according to the sector of LTC. For the sake of clarity, we provide a brief outline of the separate challenges for the healthcare and social sectors[110].

**Healthcare services**

Current legislation [111] distinguishes between internal and external quality and safety assessment of health services. The law establishes a duty for providers to implement an 'internal system of quality and safety evaluation'. It is based on institutional self-evaluation. The ministry issued a brief set of 'minimal standards'. They cover fairly basic aspects of care and its safety. The external system of quality and safety evaluation using certification by an independent authorised body is relevant only for in-patient care[112]. It is voluntary. The ministry's regulation defines a set of purely formal, administrative standards and related objectives.

Besides, there is also another measure addressing the quality and safety of health services. The ministry issues decrees that set up a very detailed regulation around minimum resources (personnel, material, and equipment). Failure to meet these requirements can lead to a loss of authorisation for health services provision. Health facilities have been facing serious personnel difficulties since 2014. Many hospitals have trouble coping with the staffing requirements. They suffer from shortages of physicians and nurses. According to some representatives of healthcare insurance companies, this is the case even for some large hospitals. A rigid implementation of the regulation faces political pressures – no large public hospital has been closed in the country yet.

**Social services**

The situation in the social care sector is different. The tools introduced by the legal framework to ensure the quality of formal services[113] are the provider's registration (each provider must be registered to provide services, registration can be withdrawn if social service quality standards are not met), inspections, and qualifications and training requirements for social workers. Current standards of quality focus on processes within institutions and on personnel capacities.

The amended Act on Social Services[114] gives clear guidance to the regional office under the delegated competence of the state to control the illegal provision of social services, i.e. social services without authorisation/registration. It is therefore the registration body that controls

[110] Quality assurance processes do not exist in informal care.
[111] Act No 372/2011 Coll. on health services and conditions for their provision (*o zdravotních službách a podmínkách jejich poskytování*).
[112] There is no specific regulation addressing the external system of quality and safety evaluation of homecare and ambulatory services.
[113] Informal care is not a subject of any quality assurance mechanism. We mention support measures for informal carers in the section 2.4.
[114] No 108/2006 Coll which entered into force 1 August 2016.

these entities and this has changed since 2016. Furthermore, a definition of those entities providing social services without authorisation was inserted. This made this illegal segment controllable and therefore punishable. The Amendment made it possible to impose a fine for the offence committed in this case up to CZK 2 million.

Quality (as well as access) could increasingly be an issue in the near future due to shortfalls in the labour force. Remuneration of employees in social services is unsatisfactory and long left unaddressed. The trade unions spoke about 'the eve of a personnel crisis' in 2017. Although wages and salaries in the care sector have increased since 2014, they are still below the average gross wage. Kubalčíková and Havlíková (2016)[115] examined the availability and quality of services for older people at regional and municipal levels. The findings suggest that the support for and availability of home-based care has declined, despite the ever-increasing number of older people and the policy preference for deinstitutionalisation. Furthermore, home-based services have failed to adjust to the growing care needs of older people (e.g., inflexible schedules, limited provision of time-demanding care, inadequate staff composition).

## 2.3 Employment (workforce and informal carers)

Given that LTC is underdeveloped and underfinanced, the employment challenge is not so obvious in this sector. The low capacity of professional home-based care and residential care is associated with great reliance on informal carers (family members). The mode of financing the sector that is supported mainly by the care allowance for older people reinforces this pattern. At the same time, needs are not adequately met. If policy response to the unmet needs for care was stronger and sought to further develop formal/professional LTC, the employment challenge would become more apparent. However, this challenge has to date been a rather low priority.

As evidenced by data (See Section 5 'Background statistics'), the LTC sector has only a modest capacity to provide care there are 2.3 LTC workers per 100 individuals aged 65+ (of the total of LTC workers 94 % are women). In the EU-27, the corresponding figure is 3.8 LTC workers per 100 individuals aged 65+ (90.8 % of the LTC workers are women). The corresponding figure in Sweden is 12 workers, in Germany 5.1 and in Austria it is 4.1 workers. National data on LTC workers is scarce (not systematically documented). Data from 2019 shows that while there were 363,300 care allowance recipients (3.4 % of the Czech population) only 28 % of them (102,700) were users of professional care. In total, the number of workers in social services was estimated at above 100,000 which was much less than the number of informal carers (see below). The main reason is that the level of allowance does not correspond to the needs of appropriate care (MLSA, 2015).

The median age of LTC workers in the Czech Republic is slightly above the 30 OECD countries´ average. It is about 47 years compared with 45 years for the OECD. Czech LTC personal carers typically have had a secondary education (90 %), only 2 % have a low level

[115] Kubalčíková, K., Havlíková, J., 'Current Developments in Social Care Services for Older Adults in the Czech Republic: Trends Towards Deinstitutionalization and Marketization', *Journal of Social Service Research* 42(2), pp. 180–198, 2016. https://bit.ly/2TXkJaJ

of education and 8 % have a high level of education. The nurses in LTC are more educated (nearly 90 % have a secondary level of education and more than 10 % have a higher education). LTC personal carers perform better in physical and mental risk indicators and stress-in-work indicators compared with the OECD countries´ average. Similarly, part-time working is at a low level (below 10 % of all LTC workers) and temporary work is also below the average of 20 OECD countries reported in the source document (about 15 %). However, 60 % of LTC workers work on shifts (this is more than the 26 OECD countries´ average) and the main problem is that remuneration is inadequate (OECD, 2020)[116].

Basically, wages of care workers in social services are lower by 22 % (residential care) and 28 % (home care) than the average wage in the Czech Republic and by 33 % and 39 %, respectively, than average wage of nurses in health care in 2019.[117] Since 2014, the government has been paying more attention to developing social services. This means, among other measures, increasing salaries in this sector and thus increasing the attractiveness of the profession (for details, see section 3). In 2019, the average wage of personal carers in institutional and home-based social services represented 78 % and 72 % respectively, of the average wage. In spite of some improvement in wages, the challenge to recruit and retain workers is a pressing current problem, not to mention what may happen in the future. The recruitment challenge is at level 4 (on the scale of 1-5) and the retention challenge is at level 5 (OECD, 2020).

With respect to the lack of professional carers, informal care is a key form of LTC. Informal carers represent 4.6 % of the population (6.2 % among women and 2.9 % among men). This is below the EU-27 average (See Section 5 'Background statistics') which is 10.3 % (11.7 % among women and 8.6 % among men). The proportion of the informal carers that provide care for more than 20 hours per week is, however, one third (both for men and women), while in the EU-27 it is only 22.2 % (24.6 % among women and 18.5 % among men). The proportion of the population over 50 that claim to serve as informal carers 'on a daily basis' is the highest in the Czech Republic among 18 OECD reported countries (OECD, 2019)[118], that is 11.6 % compared with the average of 7.2 % (data from 2017). As for national data, the number of informal carers in social services (where LTC represents a major part of care) is estimated at 250,000-300,000 people, of whom about two thirds are women aged between 35 and 64 years old. These carers provide 70-90 % of care (MLSA, 2015). Support provided to informal carers is assessed as minimal and insufficient in many respects. In particular, the rights of employed informal carers to care breaks or leaves[119] and counselling and education support are negligible and respite services are poor (MLSA, 2015). There were in total 318 registered respite care services/providers of which 230 services/providers were targeted at older people aged 65+, in the Czech Republic in April 2020.[120] Education of informal carers

[116] OECD, 'Who Cares? Attracting and Retaining Care Workers for the Elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en

[117] Own calculations based on data from the MLSA (Ministry of Labour and Social Affairs CR), *Informační systém o průměrném výdělku - Rok 2019 - Platová sféra*, [Information system on average earnings - Year 2019 - Salaries.] Praha, MPSV, 2020. https://bit.ly/2zOsAQT

[118] OECD, *Health at a Glance 2019 - OECD Indicators*, 2019. https://bit.ly/3eHiEav

[119] A new benefit and a right to the care leave has recently been established, see more in section 3.

[120] See https://bit.ly/2ZX9Ut0

is almost absent, as well as counselling (MLSA, 2015, p. 26). For this reason, the National Strategy for Social Services Development in 2016-2025 suggests that a system of education for informal carers should be established. Currently, there is a certain non-systematic offer of paid courses for professional carers in social services organised by NGOs, of which some are presented as suitable also for informal carers. Also, there are courses for informal carers provided free of charge, under projects financed by the European Social Fund; these are mainly aimed at carers for people with (special) disabilities.

## 2.4 Financial sustainability

Along with the ageing population, public LTC expenditure has been increasing. It was 0.7 % of GDP in 2013 and had increased to 1.5 % of GDP by 2019.

The 2021 Ageing Report[121] projects the expenditure to be 1.9 % of GDP in 2030 and 2.6 % of GDP in 2050 (numbers for 2030 and 2050 are similar to the EU-27 average). The 'AWG risk scenario' even suggests that due to the anticipated effect of a convergence in coverage and in real living standards across EU countries on LTC spending, the cost may reach 2.9 % of GDP in 2050.

Data (see Section 5 'Background statistics') suggest that 57.0 % of the LTC cost is spent on providing residential care, 15.4 % is spent on home care and the rest (27.5 %) on cash benefits (in 2019, 2030 as well as 2050, with a small variation in values). National data and analysis confirm the above-mentioned data, with only minor differences. Wija, Bureš and Žofka[122] show that social benefit spending associated with LTC was 0.57 % of GDP in 2017, which represented almost 43 % of total spending on LTC. Care allowance (check section 1.3 for details) represented over 90 % of all cash benefits in 2017.

There is an interesting simulation made by the National Fiscal Council (NFC, 2019)[123] on the future evolution of care allowance expenditure. The simulation was done under the assumption of a constant share of individuals drawing the allowance at a given age. With the help of demographic projection data, the analysis determines the total number of individuals drawing the benefit. The initial total volume of allowances paid was 0.5 % of GDP in 2018. It will break the level of 0.8 % of GDP in 2037 and will have risen to 1.4 % of GDP by 2060, mainly due to population ageing and an increasing share of people aged 75+ in the total Czech population.

Upon analysing factors that influence LTC spending – capacities in light of utilisation and needs assessment, subsequent needs for additional investments, wage rate and the future need for workforce – we can express a strong prediction of a constant and intensive increase in expenditure.

[121] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.
[122] Wija, P., Bareš, P. and Žofka, J., *Analýza sociálních a zdravotních služeb dlouhodobé péče v ČR* [Analysis of social and health care services of long-term care in the Czech Republic], 2019. Available in Czech at: https://bit.ly/3ecYkhS
[123] NFC (National fiscal council), *Odhady nákladů příspěvku na péči v návaznosti na stárnutí populace* [Estimates of the Costs of Care Allowance in the Context of Population Ageing], 2019. Available in Czech at: https://bit.ly/2JUViBa

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

National data (NFC, 2019) shows that the proportion of care allowance beneficiaries is mostly less than 1 % under the age of 47 for both men and women. The proportion of children aged 5-17 receiving care allowance increases with age to about 2 %. There is no particular challenge regarding LTC for other age groups[124]. They have to deal with the same issues as those discussed above. However, they (and those who care for them) may suffer even more than others from the insufficient supply of home care and respite care.

# 3 REFORM OBJECTIVES AND TRENDS

There were no structural changes (reforms) in terms of organisation or financing the whole system of LTC during the period under scrutiny. The government adopted several parametrical changes to improve access and affordability and to stabilise the workforce. A reform making changes to the organisation and quality of mental health care has been introduced.

**Access and affordability**

A new sickness insurance allowance was introduced in June 2018 to improve the financial situation of family members providing long-term care for their relatives. This new direct cash benefit is called '**long-term attendance allowance**'. The carer, whether employed or self-employed, is compensated for the loss of income from work due to caring responsibilities for a family member discharged from hospital after at least a seven-day hospitalisation and requiring at least 30 days of further care (up to a maximum of 90 days). The compensation rate is the same as in the case of short-term care. The group of potential caregivers is defined quite broadly: not only parents, grandparents, children, siblings and their spouses or unmarried partners, but also other relatives (for instance uncles or nieces of the person being cared for and their spouse or even unmarried partners). To be entitled, the carer must have contributed to the sickness insurance system for at least three months. If they are employed, the caregiver cannot be dismissed and, after the termination of their care responsibilities, they are guaranteed to return to the same job. The reform is likely to improve access to and quality of informal care. In the very first year, there were 1494 beneficiaries.

The **care allowance** for the most dependent groups of beneficiaries who are not clients of any residential care facility has been increased from April 2019 (level four) and from July 2019 (level three).

**Employment**

Since 2014, the government has been increasing salaries in the social services sector and thus increasing the attractiveness of the profession. In May 2017, the government decided

[124] Perhaps except for one exception – there has traditionally been a lack of capacities in sheltered homes for mentally disabled 18-year-old people released from residential care for children.

(MLSA, 2017a)[125] to increase the salaries of social workers and workers in social services by 23 % from July 2017. There were further increases in salaries in the public sector, social services and LTC including an increase by 10 % (November 2017) and by 10.8 % (in 2018). Latest data for 2019 (MLSA 2020)[126] indicate that while the average gross wage in the country was CZK 38,699/EUR 1425, wages of personal care workers in social services were CZK 30,356/ EUR 1118 in residential care and CZK 27,750/EUR 1022 in home-based care (CZK 34,906/EUR 1285 was the average wage for workers with a medium level of education. This means that the average wage of personal carers in these two types of social services represented 78 % and 72 %, respectively, of the average wage. This is clearly a partial improvement. However, troubles with recruitment and the stability of the workforce in LTC persist.

**COVID-19 impact**

About one-fifth of older people infected with COVID-19 and a quarter of those who died lived in retirement homes and similar facilities. According to Pšenička[127], residents of such institutions are at a far greater risk of infection than those at home. The risks also apply to staff workers. As a consequence, there are several strong voices calling for a new dynamic in the 'fading' process of deinstitutionalisation (ibid).

Similar to other professions directly dealing with COVID-19 (nurses, paramedics, physicians), social workers proved the value of their work to the public and, consequently, to politicians. Vague promises concerning a wage increase have been already made. However, it is too early to assess potential impacts of that process.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

There are significant challenges in four areas: governance, capacity building and investment, quality assurance, and home-based service support, both formal and informal.

1. **Improving the governance framework**:
    a. Further progress towards overcoming the historical split between the health and social part of LTC is needed. A coherent and integrated legal and governance framework would improve the position of all involved – clients, carers, service providers and public administration bodies and help to achieve the desirable integration of medical and social services.
    b. Responsibilities and jurisdiction over all three government levels should be defined more transparently.
2. Introducing a coherent strategy of **capacity building**:

[125] MLSA (Ministry of Labour and Social Affairs CR), *Vláda splnila slib. Platy v sociálních službách vzrostou téměř o čtvrtinu* [The government has kept its promise. Pay in social services is set to rise by nearly a quarter.], Press release, 31 May 2017, 2017a. https://bit.ly/2MeDJx7
[126] MLSA (Ministry of Labour and Social Affairs CR), *Informační systém o průměrném výdělku - Rok 2019 - Platová sféra* [Information system on average earnings - Year 2019 - Salaries.], Praha, MPSV, 2020. https://bit.ly/2XUoC1k
[127] Pšenička, J., 'Promořené domovy důchodců jako memento. Skončí ústavní péče?' [Coronavirus-infested senior homes as a memento. Is it the end of institutionalised residential care?], *Seznam Zprávy*, 1.5.2020. https://bit.ly/2ZUUzsN

a. Investment in LTC facilities should be acknowledged as one of several key middle-term priorities.

b. The funding models should allow for effective interconnections between public funds and private investment.

c. It is important to acknowledge the need for additional social workers and service providers in education policy priorities.

3. Advancing **quality control:** Some indicators that can address the impact of the services provided (e.g. clients' well-being, satisfaction and/or self-sufficiency) should be elaborated. The current set of standards should be amended to include these indicators.

4. **Encouraging and supporting home care**:

   a. Family carers need stronger support in terms of a greater availability of respite care and other home services. Their position in the labour market could be further improved by various measures such as flexible working conditions, extending the period of caregiver's allowance, respite care options, tax incentives etc.

   b. Professional providers of day and home-based services need a more predictable environment to be able to develop their services effectively. Implementation of a multiannual financial framework may be a possible option here.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 10.3 | 10.6 | 10.8 | 10.5 |
| Old-age dependency ratio, 2019 | | 20.6 | 30.4 | 35.2 | 49.8 |
| Population 65+ (in millions), 2019 | Total | 1.5 | 2.1 | 2.4 | 3.0 |
| | Women | 0.9 | 1.2 | 1.4 | 1.6 |
| | Men | 0.6 | 0.9 | 1.0 | 1.4 |
| Share of 65+ in population (%), 2019 | | 14.6 | 19.6 | 22.0 | 28.2 |
| Share of 75+ in population (%), 2019 | | 6.6 | 7.7 | 11.4 | 14.5 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 17.4* | 18.4 | | |
| | Women | 19.0* | 20.1 | 21.3 | 23.6 |
| | Men | 15.5* | 16.4 | 17.8 | 20.3 |
| Healthy life years at the age of 65, 2018 | Total | 8.7* | 8.3 | | |
| | Women | 8.8* | 8.5 | | |
| | Men | 8.5* | 8.1 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 706.7 | 806.7 | 861.2 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 368.0 | 460.2 | 579.3 |
| | Women | | 230.8 | 286.5 | 342.1 |
| | Men | | 137.1 | 173.8 | 237.2 |
| Share of potential dependants in total population (%), 2019 | | | 6.6 | 7.5 | 8.2 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 17.4 | 19.3 | 19.4 |
| Share of population 65+ in need of LTC** (%), 2019* | | 34.0 | 30.5 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 4.2 | 4.8 | 5.2 |
| Share of population 65+ receiving care at home (%), 2019 | | | 4.5 | 5.3 | 5.6 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 12.0 | 14.2 | 15.1 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 49.4 | 52.4 | 55.8 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 69.0 | 73.4 | 77.8 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 48.3 | 38.0 | | |
| | Women | 51.1 | 38.8 | | |
| | Men | 42.9 | 36.6 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 8.2 | 5.8 | | |
| | Women | 9.1 | 6.8 | | |
| | Men | 7.1 | 4.3 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 16.1 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 3.7 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 655.5 | 687.5 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|

| | | | | | |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 2.3 | 2.3 | | |
| | % Women | | 94.0 | | |
| Share of population providing informal care (%), 2016 | Total | | 4.6 | | |
| | Women | | 6.2 | | |
| | Men | | 2.9 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 33.3 | | |
| | Women | | 33.5 | | |
| | Men | | 33.0 | | |

**data not available for all Member States*

| *5.5. LTC expenditure* | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.7 | 1.5 | 1.9 | 2.6 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.7 | 1.5 | 2.0 | 2.9 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 30.1 | 57.0 | 56.4 | 56.3 |
| Public spending on home care as % of total LTC public spending, 2019 | 6.8 | 15.4 | 16.5 | 17.8 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 63.1 | 27.5 | 27.0 | 25.8 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.9 | 1.1 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.5 | 0.4 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# DENMARK

***Highlights***

- Danish long-term care (LTC) aims to increase the quality of life of people in need of care and to increase their ability to take care of themselves.
- The system consists of four types of LTC that in 2018 covered: 8.2 % of people above 65 years of age received a preventative home visit; 1.0 % undertook rehabilitation; 10.3 % received home care; and 5.6 % resided in homes for older people.
- LTC is organised by 98 municipalities, delivered by public and private providers, mainly free of charge and financed through general taxation.
- Deinstitutionalisation of LTC continues with a renewed emphasis on rehabilitative measures, and better-quality LTC by, for example, professionalising, integrating and coordinating multidisciplinary measures.
- Population ageing constitutes a challenge for the system of LTC itself, as many LTC professionals are reaching retirement age, at the same time as demand is unlikely to decrease − despite success in improving older people's health and autonomy.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The ageing of the population puts the Danish LTC system under considerably demographic pressure with a greater demand for LTC and, at the same time, fewer resources – staff and tax money – to secure the future supply of LTC.

The proportion of older people in Denmark will double from 2008 to 2050. The share of people aged above 75 years in the population increased from 7.0 % in 2008 to 8.4 % in 2019 and is projected to be 11.6 % in 2030 and 15.1 % in 2050. It is among this group that the need for LTC is increasing.[128]

At the same time, there are relatively fewer of working age to finance LTC and provide informal care.[129] In 2019, the old-age dependency ratio, defined as the ratio between people aged above 65 years and people of working age set as 15-65 years, was 30.6 %, up 7.0

[128] See Section 5 'Background statistics'. These statistics are used throughout the report unless otherwise stated.
[129] The figures used in this section are based on the 'Background statistics' to ensure comparability for all Member States. However, the statutory retirement age (SRA) in Denmark will increase from 65 years in 2018 to 67 years in 2022 and further to 68 years in 2030 and 69 years in 2035. Based on the latest projections of expected life time the SRA is expected to increase to 72 years in 2050.

percentage points (p.p.) from 23.6 % in 2008. The ageing process continues with an old-age dependency ratio of 37.3 % in 2030 and a projected ratio of 43.4 % in 2050.

Denmark's ageing process is less intensive than for the EU average. In 2019, the old-age dependency ratio for the average of the European Union was 31.4 %, up from 25.7 % in 2008 with projected ratios of 39.1 % in 2030 and 52.0 % in 2050.

Generally, older people make up a larger part of the population. In 2019, the share of people aged 65+ was 19.6 %, up 4.0 p.p. from 2008, slightly less than the average for the European Union at, respectively, 20.3 % and 3.0 p.p. The share of older people in Denmark is set to increase to 22.8 % in 2030 and 25.6 % in 2050.

Life expectancy has increased markedly in recent years. In 2019, the life expectancy at age 65 was 19.8 years, up 1.4 years from 2008. Both men and women saw more than a one year increase in this period. In 2019, men at the age of 65 years had a remaining life expectancy of 18.4 years and women 21.0 years. Therefore, life expectancy in Denmark caught up slightly with the European Union who had an average of 20.2 years in 2019, up seven months from 2008.

An increase in life expectancy does not automatically equal more healthy life years. In Denmark, for example, the expected number of healthy life years at age 65 decreased from 12.4 years in 2010 to 11.3 years in 2018. In 2018, women had 11.8 years – one year more than men, according to Eurostat data. However, a range of alternative indicators point to the opposite conclusion.[130] If extra life years will not be healthy years this might result in a greater demand for LTC. In 2018, the average number of healthy life years in the EU increased from 8.4 to 9.9.

The scale of the demographic challenges varies between municipalities (but there is a system for an economic redistribution *(Kommunale udligningsordning)* from municipalities with greater demographic needs to municipalities with lesser needs).

## 1.2 Governance and financial arrangements

The aim of social services, including LTC, is to offer services aimed at preventing need and that accommodate needs that are caused by reduced physical or mental functional capacities or by special social circumstances.

The legal basis of LTC is the Law on Social Services *(Lov om social service)* and the Law on Health *(Lov om sundhed)*.

Who is responsible for what? LTC is dealt with in different ways at the national, local and provider levels. At the national level, parliamentary politicians agree on general regulation and strike budget and other economic deals that set the economic conditions for LTC.

[130] For instance, for the period 2004-2011, a paper based on the SHARE project and also using self-rated health found that healthy life years increase more than life expectancy (https://journals.sagepub.com/doi/10.1177/1403494815569104). WHO's measure of healthy life expectancy (HALE) at age 60, indicates an increasing trend in healthy life years for Denmark. https://www.who.int/data/gho/data/indicators/indicator-details/GHO/gho-ghe-hale-healthy-life-expectancy-at-age-60.

Both social and health LTC measures are the responsibility of municipalities. Local politicians define how much should be delivered, by whom, and under what conditions. Popularly speaking, this leads to 98 municipal versions of the Danish LTC system. It is also at the local level where authorities decide on the acceptance of claimants in programmes.

At the provider level we find the organisation and the delivery of LTC. The provider can be both public and private.

The system is among one of the most universal and comprehensive in the world. It covers everybody in need of care irrespective of age, income, assets and family.

There are four types of LTC: preventative measures, rehabilitation, home care, and homes for older people. Preventative measures include preventative home visits and activities supporting good health. Rehabilitation and physical training include a medication review; nutritional intervention; ADL training (training in activities for daily living); physical aids and changes of environment; and measures addressing loneliness.

Home care covers personal care, practical help and support, and food services. Personal care consists of help in maintaining personal hygiene, to get dressed, to get out of bed, and to eat. Practical help and support covers cleaning, laundering and shopping.

There are five types of homes for older people: Nursing homes *(plejehjemsboliger)* are institutions for older people with permanent staff and service areas; sheltered housing *(beskyttede boliger)* is connected to institutions for older people, with some having permanent staff and service areas and others operating with emergency call arrangements etc.; older people housing *(plejeboliger)* consists of homes for older people with associated staff and service areas; general older people homes *(almene ældreboliger)* are designed to be suitable for older people and people with disabilities but they do not have permanent staff or service areas; and, private care accommodation *(friplejeboliger)* consists of rental accommodation for people with extensive needs for service and care, with permanent staff and service areas outside the municipal sector.

Most LTC services are free of charge. However, residents in residential care must pay rent and utilities and they may be eligible for housing support. Food is also subject to a fee. However, most LTC services are financed by general taxation that is raised at both the local and state level. Household out-of-pocket payments amounted to 0.2 % of the gross domestic product in 2017.

There is both a local and a central monitoring of LTC. Local (municipal) audits include at least one unannounced visit to nursing homes and care homes. In addition, the Danish Patient Safety Authority *(Styrelsen for Patientsikkerhed)* makes an Older People Audit *(Ældretilsyn)* at LTC units (either residential care or home care).

## 1.3 Social protection provisions

In general, LTC eligibility conditions and entitlements are based on needs only, but exactly how needs are evaluated differs across types of LTC.

Depending on their age and life situation, older people are offered a preventative visit that focuses on their functional, psychological, medical, and social resources and challenges.

Everyone over 75 years of age is offered a visit. The offer is also made to people between 65 and 79 years of age who are in a special risk group because they, for example, have lost their spouse, are isolated or have been discharged from hospital. Finally, people aged over 80 years of age are offered a visit on a yearly basis. Municipalities can organise public arrangements as an alternative to individual visits for groups that normally decline home visits.

When a person applies for home care, the municipality must offer a rehabilitation programme prior to assessing the need for home care. The goals of the rehabilitation programme are set jointly by the municipality and the older person, and the programme must be holistic and cross-disciplinary.

The amount of home care is initially decided by a municipal case worker after a home visit and is later also informed by the results of the rehabilitation programme. Home care is given to people who cannot undertake these activities themselves. Older people are offered a choice between at least two different providers of home care, one of which can be a municipal one. Albeit municipalities have different practices, many municipalities differentiate between five levels of functionality, giving rights to varying amounts and types of home care. People who cannot cook are offered food with an out-of-pocket payment of maximum of EUR 500 a month for residential care residents and EUR 7.5 per meal for people in non-residential care (2020).

For homes for older people, the needs assessment takes into account physical, mental and social aspects. If the functional capacity of the older person is markedly reduced in their existing home and it cannot be made suitable, they may be granted a place in a home for older people. After going on to a waiting list, older people must be offered a place in a nursing home or in older people housing within two months. Which accommodation the older person is allocated depends on their preferences and care needs; as well as on the local situation with regard to policies on, and vacancies in, nursing homes and in general older people homes. Older people who have been granted a place have the free choice of applying for a home in another municipality or in a specific institution. Older people who want to keep living with their spouse or partner must be offered a home suitable for two people.

Relatives to care dependent persons often act as informal carers. For example, a survey shows that close relatives of people with dementia on average spend six hours per day on nursing and care.[131] Most benefits-in-kind that support the relatives of care-dependent people are not run by public authorities but by voluntary organisations.

Certain social protection benefits support the person cared for or the carer. The universal national old-age pension (public pension, *folkepensionen*) provides a good basic income for people above pensionable age. In addition, all Danes can apply for housing support (*boligstøtte*), allowing people aged over 65 more wealth without being disqualified from any benefits. Pensioners who face difficulties making ends meet can apply for top-up social assistance. Finally, relatives to LTC claimants may receive social security while caring for

[131] Carers in Denmark, *Pårørende i Danmark – trivsel for alle i familien* (Relatives in Denmark – wellbeing for all in the family), Copenhagen, 2018. www.danskepårørende.dk (accessed 15 April 2020)

those who are terminally ill at full wage or during a care leave up to a maximum of EUR 3000 per month.[132]

## 1.4 Supply of services

Denmark has perhaps the most universal LTC system in the world. In 2018, the following were the proportion of people over 65 years of age covered by the system's four main elements: 8.2 % received a preventative home visit; 1.0 % undertook rehabilitation; 10.3 % received home care (12.9 % of women and 7.3 % of men); 5.6 % resided in elderly homes.[133]

In 2018, 91,525 people received a preventative home visit (Danmarks Statistik, 2020a). 10,633 people over 65 undertook rehabilitation. 498,600 hours of home care were offered to 146,000 claimants (including people aged below 65) giving each claimant an average of 3.4 hours of home care per week. 35.6 % of home care claimants chose a private provider. 65,712 people lived in nursing homes and other homes for older people. People aged 65-74 mostly live in general homes for older people whereas those aged above 90 mostly live in older people housing and nursing homes.

In December 2019, 280,796 old-age pensioners received housing support, including 217,312 in ordinary housing and 53,899 in homes for older people.[134] On average they received a monthly housing allowance of EUR 415 which is a substantial contribution to paying for accommodation.

The LTC sector in Denmark provides formal care that is delivered mostly by welfare professionals, that is staff with a relevant qualification. The largest group is made up by Social and Health Assistants, but there are also many nurses and trainers.

The scope and kind of activity offered differs between municipalities and includes visit schemes, workshops, education, talks, and sports for older people. The offers can be delivered by municipalities themselves, by associations and organisations, and by citizens. Users should have equal responsibility and influence on offers, and if they include older people, the local older person's council must be consulted. Food service may also be offered – that is, food prepared outside the home and brought to the older person or to a local older person centre.

It is not possible to indicate the relative size of the formal and informal sectors. However, the informal care is mainly provided by relatives taking care of older people with caring needs and to a lesser extent voluntary work, mostly organised by associations and organisations, municipalities or both. Unlike in the formal sector, carers in the informal sector generally do not have professional qualifications as carers.

[132] Kvist, J., *ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives: Denmark 2016*, European Social Policy Network (ESPN), European Commission, Brussels, 2016.
[133] Danmarks Statistik, Statistikbanken, 2020a. www.statistikbanken.dk (accessed 15 April 2020)
[134] Danmarks Statistik, *Højere pensionsalder påvirker boligstøtten* [Higher pension age influence the housing support], Nyt fra Danmarks Statistik, Copenhagen, Statistics Denmark, 2020b. www.dst.dk (accessed 15 April 2020)

However, there are patient organisations and member organisations offering relevant courses on, for example, legal aid, management, and social care. With the COVID-19 crisis most of these offers have moved online or have been cancelled.

More women than men provided informal care. In 2016, 15.2 % of the population provided informal care. The proportion of women was 17.4 % and of men 12.9 %, creating a gender gap of 4.5 p.p. In 2016, the proportion of informal carers providing more than 20 hours of care per week was 9.0 % among women and 6.9 % among men, making a total of 8.1 % overall.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

For the claimant of LTC, public support means that LTC is provided free of charge in most cases. The out-of-pocket payments are low because LTC is financed by general taxation raised at both the local and the central level. In other words, affordability is not the prime concern when it comes to LTC.[135] There are out-of-pocket payments for food services but with a limit to how much can be charged, just as people in homes for older people have to pay rent, utilities etc. But these out-of-pocket payments are, at least partly, offset by income from pension, housing support and, if necessary, top-up social assistance.

Although affordability may not be restricting access to LTC, there may be other restricting factors like demography, policies and regulation, economic budget and LTC staff. Indeed, these factors play a role in getting access to some of the LTC benefits, in particular for home care and homes for older people. Municipalities can set quality standards and decide on the level of service while always providing the necessary care.

As a result of more stringent economic frameworks, municipalities have cut coverage of certain LTC benefits despite an absence of explicit policies at the central or local level. In practice, needs assessments were made stricter and allocated hours of home care reduced. This can be seen for home care where the weekly number of home care hours has gone down. Total home care hours received by people over 65 went down by 6.4 % from 442,816 hours a week in 2016 to 414,391 in 2018 − equal to 1.5 million fewer hours of home care annually.[136] Over the same two years, the number of people receiving home care decreased slightly by 0.7 %, from 123,368 in 2016 to 122,470 in 2018.[137]

De facto retrenchment has also occurred as, while the level of provision has remained stable, the number of older people, especially those aged over 80, has gone up. For example, the number of people over 80 rose from 227,510 in 2010 to 256,694 in 2018, an increase of 12.8 %.

[135] This may also help explain why Denmark is not part of the OECD Long-Term Care Social Protection Study (OECD, *Measuring social protection for long-term care in old age*, OECD, Paris, 2019).
[136] Danmarks Statistik, 2020a, Table AED022.
[137] Danmarks Statistik, 2020a, Table AED06. This trend is also connected with the change that the rehabilitation scheme presented.

The ageing population process thus accelerates the drop in coverage. For example, the proportion of people living in homes for older people continues to fall in both absolute and relative terms. From 2016 to 2018 the number of people aged over 65 in homes for older people fell by 1.7 %.[138] However, when looking at the proportion of people aged over 75 in homes for older people, the drop is greater. From 2016 to 2018, for example, the proportion of people aged over 75 in residential care fell from 15 % to 12 %. The same decline can be noticed for other age groups. Especially those above 90 years of age, who are remaining increasingly in their own home.

Waiting times is a good measure for accessibility and unmet needs. Officially, municipalities are requested to offer a place in an LTC unit within two months.[139] However, the average waiting time was half a year in both 2016 (average of 185 days) and 2018 (186 days).[140] However, the length varies between 9-10 days in rural areas like Fanø and Læsø to 627 days in Aarhus and 1385 days in Copenhagen. In summary, access to LTC has become less universal with the gradual policy shift away from residential care to home care (started in 1987), ageing populations and de facto cuts in home care and homes for older people in recent years. Policies in the pipeline (see assessment of policy reforms below) are likely to result in more resources in home care. The drop in home care and homes for older people can only in part be ascribed to older people having generally better health and functional capacities. However, as most LTC is provided free of charge and is not dependent on work record, social divisions have not emerged.

## 2.2 Quality

There has been a great focus on ensuring quality LTC services in recent years. The key element is the Danish quality framework which is set out in this section together with some indicators on quality.

First, the framework, as described, requires municipalities to annually determine their quality standards for LTC. These include personal help and nursing, help, care and support, rehabilitation, training services, home care and residential care: these are publicly available, and used in tenders and in audits. The purpose of quality standards is to ensure that citizens get professional, dignified and qualified treatment. It is thus a common framework across municipalities that leaves considerable room for local diversity. In Frederikssund Municipality, for example, the annual quality standards for 2019 shows that training offers, and rehabilitation are provided by staff with relevant competences and that training will, on average, be offered twice a week.

The audit system that monitor and supervise units on their quality of LTC has a dual structure with a municipal system of supervision and a central system of supervision. Thus, the municipalities are required to monitor and supervise *(tilsyn)* their LTC offers. In addition, the Danish Patient Safety Authority *(Styrelsen for Patientsikkerhed)* is monitoring care for older

[138] Danmarks Statistik, 2020a, Table RESI01.
[139] The two-month limit does not apply if a citizen has asked for a specific nursing home. So waiting time can be considered only as a good measure if this is taken into account.
[140] Danmarks Statistik, 2020a, Table AED16.

people *(Ældretilsynet)*, i.e. nursing homes and home care. Unlike the municipalities, the Danish Patient Safety Authority is an independent body as it does not run any LTC services itself. Every year the authority visits about 10 % of all relevant units serving the needs of older people.

When assessing LTC quality in an audit, the Danish Patient Safety Authority works with six dimensions and 12 indicators on the quality of LTC. The dimensions cover both subjective measures, for example, wellbeing and sense of inclusion, as well as numerical measures on policies, for example, use of constraint, staff competences, and documentation. These quality measures have been established by the Danish Patient Safety Authority in collaboration with representatives from municipalities, user organisations and NGO dealing with issues relating to older people.[141]

Each audit contains five sections for each of the 12 indicators on quality that sets out: (1) the focus of the audit, (2) background (legal and substantive), (3) point of reflection, (4) references (legal) and (5) inspiration material. The audits are based on interviews and dialogue (with those needing care, relatives, management and employees), documentation analysis, and observations.

The audit aims to serve one of the objectives of the Older Person Audit, namely, to support learning locally in the care units and across the country.

The Danish Patient Safety Authority also aims to boost learning at national level. This is done through national improvement projects, thematic days and teaching material. The recent evaluation report based on 138 audits of nursing care and home care from September 2018 to February 2019 can serve as an example of such efforts.[142] On the aspect of personal autonomy and quality of life, the Authority concludes almost all management can account for their work but that 20 % of the case records contain insufficient documentation of individuals' habits and wishes and 15 % of those needing care reporting that they do not experience being autonomous, included and having a say in their own lives.[143]

Health staff can apply for authorisation with the Danish Patient Safety Authority who keeps a register of all authorised health staff. The authorisation ID is used as identification when the health professional communicates with public authorities and in other instances where there is a need to identify a person's permission to work as a health professional.

Public and private providers of LTC must be registered in the Treatment Register *(Behandlingsregisteret)* administered by the Danish Patient Safety Authority.

Citizens can complain if they are not satisfied with the quality of their LTC offer and the package of services they receive. The complaint must be addressed to the municipality which has offered the LTC benefit and/or to the provider of the LTC service. If a citizen complains

[141] Styrelsen for Patientsikkerhed, Målepunkter til Ældretilsynet på plejecentre, *hjemmeplejeenheder og midlertidige pladser* [Indicators to the Older Person Audit on nursing homes, home care and temporary places], Danish Patient Safety Authority, Copenhagen, 2019b.
[142] Styrelsen for Patientsikkerhed, *Ældretilsynet: Erfaringsopsamling fra september 2018 til februar 2019* [Older person Audit: Experiences made from September 2018 to February 2019], Danish Patient Safety Authority, Copenhagen, 2019c.
[143] Styrelsen for Patientsikkerhed, 2019c.

about a decision the municipality must review the decision and if the municipality does not change the decision their complaint must be sent to a National Board of Complaints (who also have a department who oversees that the municipalities' practices are in compliance with the laws that apply to public services). If it is a health LTC benefit the complaint can be addressed to both the municipality and the ombudsman for patients *(Patientombuddet)*.

People receiving older person care are, if possible, often involved in drawing up their LTC plans regarding what measures of training, rehabilitation and other services, that they will receive and undergo. In other words, the idea is to involve people in having a say in the LTC provided, the autonomy of older people is a quality strived for in the provision of LTC. At institutional level, interest organisations are involved in the policy-making processes through hearings and other activities.

Finally, a note on indicators. Since 2009 Statistics Denmark has published annual or biannual statistics on 19 indicators on LTC.[144] Some of these indicators relate to LTC quality, including the first indicator called 'Quality of support' which is based on satisfaction with practical help in own home, personal care in own home, practical help in nursing home, and with personal care in nursing home. Other indicators that relate to LTC quality include stability of help, number of different care staff, average days of hospital admission and of re-admissions, number of hours of home care (allocated and actually received), number of home care visits, number of home care claimants that change providers as well as number of claimants of home care, of people living in nursing homes and of people in rehabilitation and in training. In addition to these indicators, the perhaps most used indicator is the staff to older person ratio. In nursing homes, these ratios have been used to document a great variety of quality. According to the most recent survey, the ratio goes from 1.9-3.7 older person to staff on daytime shifts and from 24.4-29.5 older person to staff on night shifts.[145]

## 2.3 Employment (workforce and informal carers)

The current LTC workforce consists mainly of women and many are coming up to retirement.[146] In 2016, 94.7 % of the LTC workforce were women. In the same year there were 8.1 LTC workers per 100 individuals aged over 65, down from 8.6 workers in 2011. The Danish level of LTC workers is more than twice that of the European Union average.

At the same time, there is a dual challenge for LTC: many LTC workers are retiring at the same time as the need for LTC increases. Furthermore, there has for some years been a debate about how to better balance management and client-oriented work. One issue is how to reduce the share of management vis-à-vis the share of client-oriented workers. Another issue concerns how to enable client-oriented workers to spend time taking care of people rather than on dealing with red tape.

[144] These are available online in the statistical bank of Statistics Denmark (Danmarks Statistik, 2020)
[145] Hjelmar, U. and J.K. Jensen, *Normeringer på danske plejecentre* [Staff: Older Person ratios in Danish nursing homes], VIVDE, Copenhagen, 2020.
[146] This has been established in various studies, perhaps most notably in a report by the Association of Municipalities (Kommunernes Landsforening, Arbejdsudbud og rekruttering i kommunerne [Labour Supply and Recruitment in Municipalities], Association of Municipalities, Copenhagen, 2017.

Local and central government has for some time attempted to recruit more young people to undertake an education in social and health care − either as a social and health nurse, which takes from three years and 10 months to four years and seven months, or as a social and health assistant, which takes two years and two months. In particular, the social and health assistant track may assist people who have a marginal place in the labour market to become LTC professionals. At the same time this education increase the quality of LTC.

The pay is relatively low in the social and health care sector. To increase the attractiveness of working in the LTC sector and of undertaking relevant education, the wages and wage during internship got a boost in 2019. Other measures have been taken to reduce the numbers leaving education early and to retain workers, increase the number of educational places for nurses, and to improve the collaboration between primary school and professional schools.[147]

About half of the LTC workforce work part-time, slightly more for nurses and those working in institutions and slightly less for those providing home care.[148] However, part-time is typically 32 hours per week, only five hour less than a full-time position.

The informal carers are not supported systematically. As mentioned in section 1.3 there are some cash benefits for carers, but by far the majority of LTC offers are directed at the claimants and not their relatives. However, there are offers of respite (*afløsning*) or relief (*aflastning*) to spouses, parents, and other close relatives taking care of a person with a reduced physical or mental functional capacity. It is up to each of the 98 municipalities to decide on the quantity and quality of these respite and relief offers, which are mostly given on a discretionary basis. This is likely to lead to differing coverage and quality across municipalities and perhaps across relatives to different LTC claimant groups but this is not possible to document as the offers are neither assessed nor monitored on a systematic basis locally or centrally.

In 2016, 15.2 % of the population provided informal care, i.e. 17.4 % of women and 12.9 % of men. This is slightly more than the European Union average where 10.3 % provided informal care, i.e. 11.7 % of women and 8.6 % of men. Differences are more marked when it comes to the scope of informal care. In Denmark, 8.1 % of informal carers provide more than 20 hours of care per week which is almost a third of the average level in European Union at 22.2. 9 % of female informal carers provide 20 hours of care weekly in Denmark compared to 6.9 % of male informal carers. This is similar to figures for the European Union, which are 24.6 % for women and 18.5 % for men.

Interest organisations like the patient organisation Alzheimer's and the member organisation DaneAge Association (*Ældresagen*) organise volunteers and provide them with courses and other activities. For example, DaneAge Association has 900,000 members with 215 local

[147] Kommunernes Landsforening, *Flere hænder i ældre- og sundhedssektoren: En handlingsplan for øget rekruttering i kommunerne* [More hands in the elderly and health sector: An action plan], Association of Municipalities, Copenhagen, 2019.
[148] OECD, 'Who Cares? Attracting and Retaining Care Workers for the Elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en.

chapters and more than 20,000 volunteers carrying out social and humanitarian help such as strengthening the networks of older people.[149]

## 2.4 Financial sustainability

While Denmark has a long-term record of financial sustainability, the ageing population will make it more challenging to keep it. As described earlier, municipalities have made cuts in LTC even though this has not been an explicit policy.

Public spending on LTC made up 3.5 % of GDP in 2019, which is high compared to the EU average (OECD, 2020).

In Denmark, expenditure on home care in makes up 38.0 % of the LTC budget and on residential care 62.0 %.

The projections change the level of public spending by 1.1 p.p. of GDP to 4.6 % in 2030 and by 2.7 p.p. to 6.2 % in 2050. However, the distribution of LTC expenditure on, respectively, home care and residential care, is projected to remain fairly constant.

In the risk scenario the LTC share of GDP is somewhat higher at, respectively, 4.7 % in 2030 and 6.6 % in 2050.

In 2018, household out-of-pocket payments made up 0.2 % of GDP to LTC health.

The last few years there has been a focus on healthy ageing, welfare technologies and rehabilitation/reablement. These are all measures that aim to not only to increase the autonomy of older people but also improve public finances in the longer perspective.

LTC is currently overwhelmingly financed through tax. Making financing private could be considered, by introducing LTC insurance by shifting responsibility over to the family. A recent study found that the 55-64 age group support the existing public finance model of LTC but are doubtful that it is financially sustainable.[150] This may lead to more private insurance although it is questionable that frail older people are capable of exercising their voice in the market.[151]

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

As described, the LTC for older people is quite encompassing despite some reduction in recent years. The system of LTC for people of working age is also quite encompassing and based on a needs assessment. In other words: People may be eligible for home care, regardless of their age. Homecare takes the form of personal care and practical help and can be awarded on temporary or permanent basis or as a regular relief. Such home care can be provided independent of the family and housing situation. The person can choose between

[149] Ældresagen, *Om Ældre Sagen* (About the DaneAge Association), DaneAge Association, Copenhagen, 2020. www.aeldresagen.dk (accessed 28 April 2020)
[150] Siren, A., *Tolv scenarier for fremtidens ældre: Resultater fra forskningsprojektet MATURE* [Twelve scenarios for the future older people], VIVE, Copenhagen, 2020.
[151] Kjær, A., 'Choice and vulnerability in ageing societies: Understanding the impact of age on user capacity', *Public Administration* No 97(3), 2019, pp. 639-653.

different LTC providers. It is also possible to nominate a particular person to be the care giver pending municipal approval. Finally, the LTC is flexible, meaning that benefits can be exchange. People that have been awarded both personal and practical help can exchange these benefits within certain limits. For example, an hour of vacuuming can be exchanged for assistance to take a walk.

The needs of informal carers are still largely neglected. In light of the high employment rates for women there is no group any longer in society that can be said to have the capacity for taking care of the family's care dependent family members. Balancing work and caring may be particularly challenging for people who are parents of (adult) children with substantial care needs and for people who are (adult) children of care dependent parents.

# 3 REFORM OBJECTIVES AND TRENDS

The Danish LTC system is adapting either through commission and large reform packages or without prior planning but as the result of economic and demographic change or of a sudden external shock such as COVID-19 in spring 2020. These reform and policy changes have important implications for the accessibility, quality, employment and financing aspects of the system. This section mentions such changes, shocks and impacts as they have unfolded in the period from 1 January 2017 to 1 July 2020.

COVID-19 had a great impact on LTC in 2020 both by infecting many older people in need of care and by resulting in a series of measures to best combat the virus. Indeed, COVID-19 took its toll among LTC residents. On 31 May 2020, a total of 577 people were registered to have died with COVID-19, including 208 in residential care.[152] Unfortunately, there is no statistics on the prevalence of COVID-19 among LTC staff. However, many in LTC were most likely infected in the first part of March before restrictions on visits were made.

In Denmark, COVID-19 has mainly caused death among older people with multiple underlying conditions. Indeed, 87.5 % of people dying from COVID-19 are people aged 80 and above, where 85 % of them had comorbidities. There are more men than women dying (55.5 % of people aged 80 and above were men). Almost 80 % off all COVID-19 infections and deaths were in the Copenhagen and Zealand regions. Thus, the majority of those vulnerable to COVID-19 are likely to have received LTC and to have lived in residential care in the eastern part of the country.

This is reflected in the available statistics on LTC and COVID-19. Denmark has about 933 residential care institutions with more than 40,000 residents. In total, 124 institutions, or 13 %, have reported at least one resident with COVID-19 (Statens Serum Institut, 2020). However, this masks geographical differences from 3-5 % of residential care institutions in Jutland and Funen, over 19 % on Zealand and 38 % in Copenhagen. Put differently, the Danish figures seem to suggest that virus infection in residential care institutions is both a result of policies and the level of the virus in the environment around institutions.

[152] Statens Serum Institut, *Overvågning af COVID-19* [Monitoring COVID-19], 2020. www.ssi.dk (accessed 8 June 2020)

LTC was also affected by policy measures. Indeed, it was part of the Danish COVID-19 strategy to isolate people most vulnerable to the virus, including frail older people in residential care. From 17 March 2020, this meant that people in residential care were prohibited from getting visits in general, albeit they did have a right to visits in critical situations. The ban on visits concerned both social and health LTC institutions, except hospices.

Visits in critical situations include visits by a close relative to a critically ill or terminally sick person and visits that may be critical for the wellbeing of a resident with reduced cognitive skills who can therefore not understand the restrictions on visits. Deteriorating mental capabilities in themselves do not qualify as a critical situation. People with dementia can therefore not receive visits, unless the manager of the residential care institution judges that a cognitive reduction means the resident does not understand and accept the rules on visit restrictions.

The laws were passed by the government and required the municipalities responsible for LTC to follow the guidelines of the Danish Patient Safety Authority and to communicate their guidelines on municipal websites where discretion is sometimes placed with managers of LTC units.

The management of the individual care centres or residences must ensure that visits from relatives, both indoors and outdoors, take into account the Danish HealthAuthority's recommendations on, among other things, good hygiene and that the visits are carried out safely. The recommendations include, inter alia, management's responsibility and planning of visits, including that visitors should be without symptoms of respiratory illness such as a cough, cold or other symptoms that may give rise to suspicion of COVID-19, for 48 hours prior to the visit.

The Danish Patient Safety Authority and the State Serum Institute are also closely monitoring the development of the spread of new COVID-19 cases in the municipalities across the country. If the infection rate in a municipality exceeds a certain level, the Danish Patient Safety Authority will contact the municipality and inform and advise on how to handle the situation. Municipalities can also seek advice on limiting the spread of infection by contacting the Danish Patient Safety Authority.

Funds has been given to municipalities as well as to the NGO's such as the DaneAge Association and the Alzheimer's Association, including their local associations, to provide information and individual advice to debilitated older people, including those with dementia and their relatives, on how to deal with the consequences of COVID-19.

Funds have also been allocated (operating grants) for the older telephone (counselling, prevention of loneliness, etc.), which targets older people who sit in isolation at home and miss company. The funds can be used to recruit more volunteer 'telephone friends' and have more time to match phone buddies, as well as to be able to spread awareness of the scheme to more lonely older people who have no knowledge of the older people's telephone in advance.

Other parts of LTC have been impacted more widely by COVID-19 than residential care. On 4 April 2020, the government issued a law that temporarily puts limits on rights to healthcare

and LTC in order to allow regional and local authorities to prioritise treatment, care and staff in connection with COVID-19.[153] Of particular relevance to LTC, the law authorises municipalities (temporarily) to prioritise the use of resources on treatment of patients with life critical and acute needs over the preventive and health promoting services to people, preventative visits, training offers and the two months guarantee to residential care. Also, the municipality can decide to stop or reduce LTC offers. However, the municipality must only make such decision based on concrete and individual assessments and cannot use the law to make general reductions of LTC. This is also the case for decisions to stop or reduce rehabilitative programmes and respite offers. There is no consolidated picture of what the 98 municipalities have done with respect to LTC.

Finally, some residents and their relatives has expressed fear about becoming infected by home care staff which may have resulted in some residents declining home care leading to problems concerning take up. This has led DaneAge to call for clear guidelines to avoid LTC staff contaminating older people.[154] The Board of Health issued material regarding this in April.

Before COVID-19 there were also some noteworthy developments. Entitled 'A secure and dignified life with dementia', the national action plan on dementia 2025 was launched in January 2017. To substantively improve measures for dealing with dementia and to reduce geographical differences, the plan has three aims over the period to 2025: 1) all (98) municipalities should be dementia-friendly; 2) more people should receive a timely and adequate diagnosis, with 80 % having a specific dementia diagnosis; and 3) improved nursing and treatment should reduce the use of antipsychotic medicine among people with dementia by 50 %. This has resulted in 23 initiatives linked to five focus areas: early detection and better quality in patient inquiry and treatment; better-quality nursing, care and rehabilitation; support and counselling for relatives of people with dementia; dementia-friendly communities and housing; and increased knowledge and competence levels.

There have not been reforms addressing access to LTC during the period but as described above the access to home care and homes for older people especially have become stricter due to demographic developments and de facto harder interpretations of what it takes to qualify for LTC.

As the financing of LTC is largely public and the population is ageing one would perhaps have expected changes in cost sharing arrangements. However, this has not happened.

The quality of LTC has been addressed by requesting municipalities to work with quality standards and make these publicly available (see section 2.2). However, it has not yet resulted in a quality framework programme as in healthcare.[155]

[153] These rules have been lifted as of 1 July 2020.
[154] www.aeldresagen.dk
[155] IKAS, *Introduction to DDKM* (Danish Healthcare Quality Programme), the Danish Institute for Quality and Accreditation in Healthcare, Copenhagen, 2020. https://www.ikas.dk/den-danske-kvalitetsmodel/ddkm-in-english/introduction-to-ddkm/ (accessed 13 April 2020)

There have been attempts to attract and retain workers to the formal care sector following the action plan 'More hands in the older person and health sector' of the Association of Municipalities from 2018. These have not least attempted to get more young people to start training as home and health care assistants or helpers. The measures span information campaigns, higher wages, and better collaboration between relevant partners to attract, educate and retain more workers.

The dignity of older people, which started as an overarching policy concern in 2016, continues to be at the centre of many reforms. In 2018 this was, for example, confirmed with a series of initiatives to strengthen older people's autonomy, improved access to local communities and better terminal care.[156]

The successful preventative visit has incrementally been expanded to more older people and to cover more issues; most recently, in 2019, to people over 70 years of age and to tackle loneliness.

New measures are being introduced to continue the long-term trends toward more autonomy for older people and independent living. The integration of rehabilitation in home care has markedly expanded the scope of social investment or active ageing. By developing, reinstating and maintaining functional capacities, rehabilitation aims to allow older people as much autonomy as possible. In the 1990s, less institutionalisation was secured through more home care and fewer nursing homes. Since the late 1990s the same trend has seen the establishment of new forms of housing for the older people.

Finally, there is a trend towards more and more external auditing. To ensure the quality of LTC and to prevent abuse of individuals, municipalities and the Danish Authority of Patients Security have been obliged to undertake audits. The Danish Authority of Patients Security audit was introduced in 2018 following debate that the internal audit by municipalities risked being biased. Thus, the audit by the Danish Authority of Patients Security is a new initiative that runs from July 2018 to 31 December 2021 as a pilot project and is subject to on-going evaluations.[157]

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

There is no easy way to save money in older person care without reducing the scope or quality of home care or homes for older people. However, LTC reforms addressing needs of ageing populations and lessons learned from COVID-19 could offer opportunities for improvements, even in an already well-functioning system. More effective and cost-efficient measures might include an even stronger emphasis on rehabilitation and social investments. This calls for evidence-backed interventions. In January 2018, the National Board of Social Services launched the socio-economic investment model (*socioøkonomisk investeringsmodel*, SØM), which can help municipalities and other actors assess the economic returns on social

[156] Sundheds- og Ældreministeriet, *Værdighed i ældreplejen: En hjertesag* [Dignity in Older Age Care], Ministries of Health and Older People, Copenhagen, 2018.
[157] Styrelsen for Patientsikkerhed, *Ældretilsynet* [Older People Audit], Danish Patient Safety Authority, Copenhagen, 2019a. https://stps.dk/da/tilsyn/aeldretilsynet/ (accessed 23 September 2020)

investment measures for people of working age. In 2018, work on the SØM is aimed at extending it to children and young people. One possibility is to extend the SØM further to also include rehabilitation and social investment measures for older people. This could prove important for the further expansion of rehabilitation measures, and provide a bulwark against budget cuts.

The idea of working toward measures that are more integrated, holistic and multi-disciplinary, is well reflected in current reform thinking. However, plans may be good on paper, but if they are not backed by action, their potential may not materialise.

Despite there being a greater emphasis on involving relatives (and voluntary workers), the special needs of family relatives are not yet properly addressed. This is reflected in the policy recommendations of Carers in Denmark (2018), which include better legal recognition, rights for carers in various domains, providing education for all carers and care consultants in municipalities and hospitals, and the right to practical and psychological help. Perhaps dementia and Alzheimer's disease are the two areas where most progress has been achieved in addressing the needs of relatives. Hence, there has been an Alzheimer plan for some time and the national dementia action plan 2025 also reflects a greater inclusion of relatives.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 5.5 | 5.8 | 6.0 | 6.1 |
| Old-age dependency ratio, 2019 | | 23.6 | 30.6 | 37.3 | 43.4 |
| Population 65+ (in millions), 2019 | Total | 0.9 | 1.1 | 1.4 | 1.6 |
| | Women | 0.5 | 0.6 | 0.7 | 0.8 |
| | Men | 0.4 | 0.5 | 0.6 | 0.7 |
| Share of 65+ in population (%), 2019 | | 15.6 | 19.6 | 22.8 | 25.6 |
| Share of 75+ in population (%), 2019 | | 7.0 | 8.4 | 11.6 | 15.1 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 18.4* | 19.8 | | |
| | Women | 19.7* | 21.0 | 22.2 | 24.4 |
| | Men | 17.0* | 18.4 | 19.5 | 21.5 |
| Healthy life years at the age of 65, 2018 | Total | 12.4* | 11.3 | | |
| | Women | 12.8* | 11.8 | | |
| | Men | 11.8* | 10.8 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 378.5 | 427.6 | 465.2 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 141.2 | 192.3 | 240.4 |
| | Women | | 80.5 | 108.5 | 137.7 |
| | Men | | 60.7 | 83.8 | 102.7 |
| Share of potential dependants in total population (%), 2019 | | | 6.5 | 7.2 | 7.6 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 12.3 | 14.0 | 15.4 |
| Share of population 65+ in need of LTC** (%), 2019* | | 14.0 | 14.9 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 4.6 | 5.5 | 7.0 |
| Share of population 65+ receiving care at home (%), 2019 | | | 14.3 | 16.9 | 19.8 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 153.1 | 159.6 | 173.5 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 46.2 | 43.0 | | |
| | Women | 48.5 | 48.3 | | |
| | Men | 42.3 | 35.0 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 14.2 | 13.5 | | |
| | Women | 17.4 | 15.0 | | |
| | Men | 10.4 | 11.8 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | - | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | - | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 889.2 | 750.2 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 8.6 | 8.1 | | |
| | % Women | | 94.7 | | |
| Share of population providing informal care (%), 2016 | Total | | 15.2 | | |
| | Women | | 17.4 | | |
| | Men | | 12.9 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 8.1 | | |
| | Women | | 9.0 | | |
| | Men | | 6.9 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 2.4 | 3.5 | 4.6 | 6.2 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 2.4 | 3.5 | 4.7 | 6.6 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 43.6 | 62.0 | 62.2 | 63.3 |
| Public spending on home care as % of total LTC public spending, 2019 | 51.0 | 38.0 | 37.8 | 36.7 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 5.4 | 0.0 | 0.0 | 0.0 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 2.3 | 2.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.2 | 1.1 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.2 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# GERMANY

***Highlights***

- The need for long-term care (LTC) will increase considerably in the coming decades. By 2050, the number of potential dependants is expected to rise from the current figure of about 5. 8 million to 6.6 million.
- LTC in Germany is organised according to the insurance principle. The entire resident population is obliged to pay compulsory insurance contributions for LTC and is entitled to benefits from the LTC insurance scheme (LTCI). Even though the entitlement to benefits is quite comprehensive, LTCI may only cover part of the costs of long-term care. The rest is covered by people in need of LTC themselves or – if necessary and under certain conditions - by immediate family members or social assistance.
- The most recent reforms, adopted between 2015 and 2019, were aimed at extending eligibility for benefits by reforming the definition of 'in need of care' and the associated assessment method, enhancing the attractiveness of care professions and strengthening the quality of LTC.
- The greatest challenge is the recruitment of a sufficient number of professional LTC staff, as staff shortages will continue to rise due to demographic and social change. The shortfall of professional LTC staff is estimated at up to approximately 186,000 full-time equivalents in LTC facilities in 2030. In order to successfully tackle the shortage of professional LTC staff a significant increase in salaries and a significant improvement in working conditions are required.
- Further major challenges are to improve the quality of LTC and to reduce privately borne costs for care.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LTC SYSTEM(S)

### 1.1 Demographic trends

The population of Germany is among one of the oldest in the European Union.[158] In 2019, 17.9 million people were aged 65 and over, amounting to 21.5 % (EU: 20.3 %) of the total population (83.0 million).[159] The German population will continue to age in the coming decades while the total population is projected to remain almost constant (83.5 million) until 2030 and to decrease slightly to 82.7 million in 2050. The number of people aged 65+ (share of total population) is predicted to rise to 21.2 million in 2030 (25.4 % of the population) and

[158] Eurostat, *Ageing Europe: Looking at the lives of older people in the EU: 2019 edition*, 2019. https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19 %E2 %80 %91681-EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893.

[159] All data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.

to 23.2 million in 2050 (28.0 % of the population) (EU-27[160] 2030: 24.2 %, EU-27 2050: 29.5 %). The share of people aged 75 and over in the total population was 11.4 % in 2019 (EU: 9.7 %) and will increase to 12.1 % in 2030 (EU: 12.0 %) and to 16.9 % in 2050 (EU: 17.1 %). In 2019, the average life expectancy at the age of 65 was 19.9 years (21.4 for women, 18.3 for men), and the average healthy life expectancy in 2018 was 11.9 years (12.2 for women and 11.5 for men). According to the most recent population projection by the German Federal Statistical Office, the number and share of people aged 80 and over will grow particularly fast between 2030 and 2050 and is estimated to be between 8.9 and 10.5 million by 2050.[161]

Data shows that the risk of being in need of care depends to a high degree on age: In 2017, 70.7 % of people aged 90 and over are in need of care. Because there is a close link between age and the need for care, the number of people in need of care will also grow significantly in the decades ahead. Again, projections differ according to the underlying assumptions, e.g. the age-specific LTC dependency rate or the number of people eligible for LTC.[162] Nevertheless, experts agree that the number of people requiring care will rise considerably. The Federal Ministry of Health puts the number of people in need of LTC in statutory LTCI (without private LTCI) at 4.6 million in 2030 and 5.8 million in 2050[163].

The total number of potential dependants will increase from 5.79 million in 2019 to 6.59 by 2050, the proportion in the total population rising from 7.9 % to 8.9 %. The official German statistics record only those people in need of care receiving LTC insurance benefits. According to the latest figures, around 3.92 million people received LTC at the end of 2018 (Bundesministerium für Gesundheit, 2020a, p. 1), among them 3.69 million people received statutory LTCI and 0.23 million private LTCI. In 2017 the number of people entitled to benefits has expanded greatly (see section 1.3).

## 1.2 Governance and financial arrangements

LTC in Germany is based on the insurance principle. The structure and organisation of the LTC insurance scheme (LTCI) is closely linked to the principles of the German health insurance system. Anyone living in Germany is obliged to take out LTCI, either in the statutory or the private LTCI system. In LTCI, the 'LTC insurance follows healthcare insurance' principle applies, i.e. all statutory health insurance members are, in general, automatically members of the statutory LTCI, and all members of a private health insurance are members of a private LTCI. The services provided by private LTCI are equivalent to those offered by statutory LTCI. By the end of 2018, 72.75 million people (around 89 % of

[160] EU-27 refers to the current 27 Member States of the European Union.
[161] Statistisches Bundesamt, *Bevölkerung im Wandel. Annahmen und Ergebnisse der 14. koordinierten Bevölkerungsvorausberechnung*, Wiesbaden: Statistisches Bundesamt, 2019, p. 25. https://www.destatis.de/DE/Presse/Pressekonferenzen/2019/Bevoelkerung/pressebroschuere-bevoelkerung.pdf?__blob=publicationFile.
[162] Rosenbrock, R. and Gerlinger, T., *Gesundheitspolitik. Eine systematische Einführung, 3. Aufl.*, Bern: Verlag Hans Huber, Bern, 2014.
[163] Bundesministerium für Gesundheit, *Zahlen und Fakten zur Pflegeversicherung, Stand: 17. Februar 2020*, 2020a, p. 17. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/Statistiken/Pflegeversicherung/Zahlen_und_Fakten/Zahlen_und_Fakten_der_SPV_17.Februar_2020_barr.pdf.

the population) were insured under the statutory LTCI scheme, while 9.24 million (around 11 %) held a private LTCI policy[164].

Statutory LTC insurance is financed through income-related contributions paid equally by employers and employees. In 2020, the contribution rate was 3.05 % of gross income, payment to be divided equally between employers and employees. Childless contributors are required to pay an additional contribution rate of 0.25 %. Children and spouses with an income of less than EUR 450 per month are co-insured at no extra cost. Rather than being calculated on the basis of income, premiums for private LTC insurance are graded, as with private health insurance, according to age on commencement of the policy, whilst contributions are capped by law. The premiums for men and women are equal. Children receive free cover, as they do under statutory LTC insurance.

LTCI covers only part of LTC costs. The amount received varies depending on the degree of care and the type of benefit provided. In residential care, benefit recipients often have to make substantial co-payments (see section 2.1). If the persons in need of care - or under certain conditions their immediate family members - are not in a position to bear the uncovered costs themselves, the remaining amount must be paid by social assistance grants, i.e. by the municipalities. In 2019, expenditure on social assistance grants for LTC amounted to EUR 4.0 billion[165], i.e. 0.12 % of GDP or 9.7 % of total statutory LTC expenditure (see section 2.4).[166] Supplementary private insurance can be an option to purchase additional coverage.

The legal framework for LTCI is laid down by the federal state, including the benefits list, the contribution rate and the rights and obligations of all involved such as the *Länder*, the LTC funds, the service providers and the people in need of care. According to the regulatory principles of the German healthcare system, broad legal stipulations are to be given concrete form in collective negotiations and agreements concluded by those involved (LTC funds and LTC providers or their associations) and self-administered bodies, which are monitored by the state. These agreements and contracts mainly contain provisions on remuneration and quality assurance. The service providers are primarily responsible for the quality of the services provided, while the *Länder* and local authorities are responsible for providing an adequate LTC infrastructure[167].

## 1.3 Social protection provisions

According to the law, people are eligible for LTC if, because of a physical, mental or psychological illness or disability, they require frequent or substantial assistance with a specific set of activities of daily living and instrumental activities of daily living for an estimated period of six months or longer. All dependent people (children with disabilities, adults and older people) are eligible for the LTCI care scheme, irrespective of their age. If

[164] Bundesministerium für Gesundheit, 2020a, p. 1.
[165] Statistisches Bundesamt, *Ausgaben und Einnahmen der Sozialhilfe im Laufe des Berichtsjahres in 1.000 Euro. Gliederungsmerkmale: Jahre, Region, Ausgaben/Einnahmen (Hilfeart), Träger, Ort der Leistungserbringung*, 2020a. www.gbe-bund.de.
[166] These are the gross expenses. In 2019, care assistance only spent EUR 3.8 billion net.
[167] Rosenbrock and Gerlinger, 2014).

people in need of care are not able to cover out-of-pocket payments according to the legal provisions, social protection systems would cover the full cost of LTC.[168] Regular LTCI benefits do not differ between regions and are not limited in time.

LTC benefits are granted on the basis of a care grade and of the care arrangements (either at home or in a residential care setting).

Access to benefits was significantly expanded from 2017. Since then, the entitlement to benefits is banded into five care grades based on physical, mental and psychological disabilities. Accordingly, the condition of being 'in need of care' is determined by the degree of the individual's autonomy, i.e. by impairments of independence or incapacitation in six fields (modules), which are weighted as follows: mobility (10 %), cognitive and communicative abilities, behaviour patterns and psychological problems (15 %), level of self-sufficiency (40 %), health restrictions, demands and stress due to therapies (20 %) and structure of everyday life and social contacts (15 %). The grade of care is determined by the Medical Services of the Statutory Health Insurance Funds (*Medizinischer Dienst der Gesetzlichen Krankenversicherung – MDK*) or by its private counterpart.

In general, a recipient may choose between three different arrangements: a care allowance, home care (in kind), and residential care:

- Care allowance refers to informal care, i.e. the person in need of care receives only monetary support, typically lives at home and is looked after by close relatives.
- Home care (in kind) means that a professional care provider (such as a home care service) visits the recipient regularly at home. The provider is under contract to the LTCI fund and is paid directly by LTCI up to a fixed sum according to the care grade.
- Residential care refers to a stay in a residential home and includes day and night care in Germany. The LTC insurance policy will pay expenses for basic care, social support and treatment according to the care level. As with home care, people in need of care are responsible for paying the costs of food and board.

In 2016, according to a survey, 24 % of households that categorising themselves as in need of LTC did not use professional home care services either for financial reasons (19.2 %) or because services were not available (3.8 %).[169] More recent data from the Federal Ministry of Health for 2018 shows that most of the people in need of care who receive benefits or services from statutory LTCI are in receipt of a care allowance; this applied to 48.3 % of all recipients in 2018 (including combined benefits: 62.1 %).[170] Conversely residential homes constitute the most expensive form of care and account for about 31.4 % (2018) of total

[168] Cravo Oliveira Hashiguchi, T. and Llena-Nozal, A., 'The effectiveness of social protection for long-term care in old age. Is social protection reducing the risk of poverty associated with care needs?', *OECD Health Working Paper* No. 117, OECD, 2020. https://www.oecd-ilibrary.org/social-issues-migration-health/the-effectiveness-of-social-protection-for-long-term-care-in-old-age_2592f06e-en.

[169] EU-SILC data 2016: ilc_ats_15.

[170] Bundesministerium für Gesundheit, *Leistungsempfänger der sozialen Pflegeversicherung im Jahresdurchschnitt nach Leistungsarten (errechnet aus Leistungstagen)*, 2020b. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/Statistiken/Pflegeversicherung/Leistungsempfaenger/06-Leistungsempfaenger-der-sozialen-PV-nach-Leistungsarten_2018.pdf.

expenditure.[171] The number of people in need of care living in residential homes is not rising as quickly as the number of those receiving home care. The number of people living in residential homes has even stagnated recently.[172]

Besides these core benefits, there are additional benefits provided under LTCI, for example:

- Holiday stand-ins/respite care: if the person who provides care at home goes on holiday or is otherwise unable to provide care, people in need of care are entitled to a stand-in for a maximum of six weeks a year.
- Part-time institutional day and night care: part-time residential care refers to care in a facility that provides day or night care. The LTCI fund pays the costs of care, social support and medical treatment.
- Short-term care: short-term care is provided in appropriate institutional facilities if the people in need of care only need full-time residential care for a certain period of time, notably to cope with crises in care at home or following a stay in hospital.
- Nursing aids (such as a special bed) and home conversion grants to accommodate the nursing care needs.
- Nursing care courses for relatives (advice for informal caregivers).
- Case and care management (advice and counselling for persons in need of LTC and informal carers)

With regard to benefits, there are no differences between statutory and private LTCI.

Apart from benefits for people in need of care themselves, the law also provides benefits for close relatives who organise or provide LTC. In order to balance the demands of care and work needs, employees are legally entitled, regardless of status, to reduce their working hours by at least 15 hours for up to 24 months, including a maximum of six months' time off work (or below 15 hours per week). There is a guaranteed right of return from temporary part-time to full-time work or the working hours before having taken the leave. Employees taking up this scheme can claim a credit-financed benefit (interest-free loan) that has to be paid back in stages. In addition, employees are entitled to short-term care leave of up to 10 working days without prior notice. This right provides the opportunity to organise assistance and support when an acute care situation involving a close relative arises. The loss of income is compensated by an wage compensation benefit (caregiver allowance) amounting to 90 % of the lost earnings (minus employee contributions to the statutory pension, LTC and unemployment insurance, comparable to sickness benefit in the case of a child's illness).

The entitlement to short-term absence from work is unlimited; it applies to every employee irrespective of the size of company. However, the statutory right to the six months' care leave

[171] Bundesministerium für Gesundheit, *Die Finanzentwicklung der sozialen Pflegeversicherung Ist-Ergebnisse ohne Rechnungsabgrenzung*, 2020c. https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/3_Downloads/Statistiken/Pflegeversicherung/Finanzentwicklung/Finanzentwicklung-der-sozialen-Pflegeversicherung_2018.pdf.

[172] Increase of people living in residential nursing homes in 2017: 0.8 %, in 2018: 1.6 %, in 2019: 0.6 %, Federal Ministry of Health of the Federal Republic of Germany.

is limited to employees in companies with more than 15 employees. And the statutory right to work part-time for up to 24 months applies only to employees in companies with more than 25 employees. Those entitled are spouses, partners in accordance with the cohabiting partnership law or equivalent partnerships, siblings, parents, step-parents, grandparents, parents-in-law, children, children-in-law, adopted or foster children, adopted or foster children of the spouse or life partner, stepchildren, grandchildren, as well as brothers- and sisters-in-law.

Under certain conditions, people who provide informal[173] care to care-dependent people can acquire a pension entitlement, if they care for one or more people insured in a statutory or private long-term care insurance with care level 2 or higher. In this case, the long-term care fund pays the pension contributions for the respective caregiver. These contributions are paid as long as the caregiver cares for the care-dependent person and is therefore not limited in time. As the care period is counted like periods of employment in the statutory pension insurance, the care period can raise the caregiver's pension as well as prolong the waiting period for the entitlement to statutory pension (at least five years).

**Supply of Services**

On the supply side, the LTC market is dominated by private providers. In 2019, there were 15,380 residential homes and 14,688 home care providers (Statistisches Bundesamt, Pflegestatistik, 2020). 43 % of all nursing homes were private, for-profit establishments, 53 % private not-for-profit establishments and 5 % publicly owned and run. In the field of home care (outpatient LTC services), as many as 67 % of providers were private, for-profit establishments, 32 % private, not-for-profit establishments and 1 % were publicly owned and run.[174] Around 422,000 (mostly qualified) people are employed in home care services, and around 797,000 (also mostly qualified) people are employed in residential homes for older people (Statistisches Bundesamt, 2019).

By the end of 2019, almost 3.31 million (80 %) of the approximately 4.1 million people in need of LTC were cared for at home, 0.82 million (20 %) in nursing homes. Of the 3.31 million people who received care at home, 2.12 million (64 %) were cared for by relatives and 0.98 million (30 %) were cared for jointly by relatives and outpatient care services (Statistisches Bundesamt 2020). Thus, the large majority of people in need of care are still attended to, and cared for, by their family members, mostly spouses, daughters and daughters-in-law, around 60 % of whom are employed.[175]

[173] Informal care in this context means provision of care in a non-commercial way.
[174] Statistisches Bundesamt, *Pflegestatistik. Pflege im Rahmen der Pflegeversicherung. Deutschlandergebnisse*, Statistisches Bundesamt, Wiesbaden, 2018. https://www.destatis.de/DE/Themen/Gesellschaft-Umwelt/Gesundheit/Pflege/_inhalt.html#sprg229948
[175] Geyer, J. and Schulz, E., 'Who cares? Die Bedeutung der informellen Pflege durch Erwerbstätige in Deutschland', *DIW-Wochenbericht* 81(14), 2014, pp. 294-301.

# 2 ASSESSMENT OF THE LTC CHALLENGES FACING THE COUNTRY

## 2.1 Access and affordability

The criteria for determining the need for care, the provisions for assessment and the introduction of five care grades, as outlined above (see section 1.3), were part of a major reform that came into force in 2017, replacing the previous restriction of eligibility to physical disabilities (including the assessment of need in minutes per day). It extended eligibility particularly to people suffering from dementia and thus represented a crucial improvement in access to LTC. To that extent, legal entitlement to LTC benefits in Germany is quite comprehensive.

Nevertheless, as noted above, LTCI covers only part of the costs of LTC. The amount received varies depending on the degree of care and the type of benefit provided. The shortfall must be paid privately by the person in need of care.[176] If regular income is not sufficient, the person in need of care or their spouse must draw on savings or property (up to a defined limit).

The private share of LTC costs has increased since LTC insurance was established in 1995. Between 1995 and 2008, LTCI benefits were not raised. Since 2008 the § 30 SGB XI provides for a review of the LTCI benefits with a view to price developments every three years. The most recent review took place in 2020. As for 2017, the private costs of LTC were estimated at EUR 11.2 billion (21.4 % of total expenditure on LTC, estimated at EUR 52.2 billion). Accordingly statutory LTCI covered some 68.1 % and private LTCI 2.5 % of total LTCI expenditure.[177]

The children of those in need of care can find themselves liable to pay considerable sums for their parents' care. Against this background, the 'Relatives' Burden Reducing Act' (*Angehörigenentlastungsgesetz*) was adopted in 2019 which stipulates that only those children or parents of those in need of care whose annual gross income exceeds EUR 100,000 shall be obliged to cover the remaining costs of LTC. These provisions notwithstanding, LTCI still covers only part of the costs of LTC and may impose very high costs on those in need of LTC, particularly those in residential homes. It is one of the main challenges for LTC insurance to abolish or to reduce these private shares considerably.

Initially, the introduction of LTC insurance considerably reduced the number of recipients depending on social assistance grants to pay for their LTC. Since the system reform in 2017

[176] Due to the exemption of children or parents with an annual income of up to EUR 100,000/year and people, children are hardly eligible for recourse under the Relief Society Act.
[177] Rothgang, H. and Müller, R., *BARMER GEK Pflegereport 2019: Ambulantisierung der Pflege*, Barmer, Berlin, Wuppertal, 2019. https://www.barmer.de/blob/215396/a68d16384f26a09f598f05c9be4ca76a/data/dl-barmer-pflegereport-2019.pdf

their share is less than 10 % of all dependants; in 2018 less than 300,000 people received social welfare grants for LTC[178].

## 2.2 Quality

The quality of LTC is a matter of major concern in Germany. The latest LTC quality report submitted by the Medical Review Board of the National Association of Statutory Health Insurance Funds (*MDS*) found that in 2016 many residential homes and domiciliary services met the requirements of good care, but severe flaws continued to exist, e.g. the recording of pain management and wound care in residential homes as well as intensive care (24 hour care for people in most need) and care counselling in domiciliary care were inadequate (see for more details: MDS, 2018). Though the provisions for eligibility and benefits in LTCI were modernised (see section 1.3), it remains to be seen how the new term 'in need of care' will be implemented in practice.

The legal framework stipulates a broad range of requirements (e.g. for ensuring LTC quality, an adequate LTC infrastructure or an adequate counselling for people in need of care and their relatives) that have to be met when providing LTC. These requirements apply to home-based care as well as to residential settings.

LTC providers are responsible for the quality of their services, including quality assurance and improvement[179]. In order to assure quality, LTC providers are obliged to establish and fine-tune an internal quality management system and to adopt expert standards. The associations of LTC Funds, LTC providers and municipalities have to ensure that expert standards for LTC will be established in order to assure and improve the quality of LTC. Expert standards comprise guidelines on particular problems encountered in the provision of care (e.g. bedsore prophylaxis). These standards are to be based on scientific knowledge and independent expertise and are to be continuously updated in accordance with the current knowledge. Expert standards give concrete form to the commonly accepted current knowledge in medicine and care[180].

High-quality care requires adequate staffing. In this context, a project to develop and test a valid, science-based procedure for the calculation of adequate staffing levels in LTC facilities according to section 113c Social Code Book XI was completed on 30 June 2020. It recommends a procedure to determine the specific staffing mix for (fully) residential LTC facilities that takes into account the needs of all residents according to their care grades. Nursing tasks are to be assigned to the care workers in correspondence to their qualifications and competences. There are separate recommendations for the homecare sector (out-patient) LTC services. Against this background, the Federal Ministry of Health has initiated a road map process following the respective agreement of the Concerted Action for the Care

[178] Statistisches Bundesamt, *Empfänger und Empfängerinnen von Leistungen nach dem 5. bis 9. Kapitel SGB XII – Sozialhilfe im Laufe des Berichtsjahres (Anzahl und je 100.000 Einwohner). Gliederungsmerkmale: Jahre, Region, Geschlecht, Ort der Hilfegewährung, Hilfeart*, 2020b. www.gbe-bund.de
[179] Section 112 Social Code Book XI.
[180] Section 113a para 1 Social Code Book XI.

Workforce (see 2.3) and with the participation of the relevant actors. This road map depicts the time plan and order of the necessary steps to implement the recommended procedure.

The Medical Services of the Statutory Health Insurance Fund and the corresponding service of the private health insurance system are authorised and obliged to monitor whether the accredited LTC providers meet the legal requirements for care quality[181]. Inspections of accredited residential homes are to be carried out without prior warning if LTC providers do not submit certain data on their organisations' outcome quality as required by law. Experts from the regulatory bodies are entitled to access LTC providers' buildings and grounds at any time (section 114a para 2 Social Code Book XI). The associations of LTC funds have to ensure that the Medical Review Board of the statutory health insurance system, the corresponding private board or accredited experts check or audit LTC facilities at least once a year. Audits or checks have to focus on outcome and process quality and may be extended to aspects of structure quality[182]. All results of audits and checks are to be published in full on online.

Strengthening informal care at home (by close relatives or volunteers) is one of the major objectives of LTC policies, particularly as it is the wish of most people in need of care to stay in their homes. In effect it is also an important factor to cope with the overall shortage of LTC professionals. However, pursuing this objective raises the problem of how to ensure the quality care provided by non-professionals. Consequently, there is concern about how to support informal care-givers. Thus, since 2008, LTCI organisations have been obliged to offer free LTC training courses for family members and unpaid carers. These courses aim to promote and strengthen social engagement, facilitate care and reduce or prevent physical and mental stress. These courses are also designed to teach the skills required for autonomous delivery of care[183]. Recipients of LTC allowances (*Pflegegeld*), i.e. those people who receive care from informal carers, are obliged to make use of regular counselling services regarding LTC[184]. These counselling services have to be provided by accredited LTC organisations every six months (care level 2 and 3) or quarterly (care level 4 and 5). Counselling is intended to help ensure the safety of people in need of care and the quality of care. Those involved in the self-administration of LTC have to agree recommendations on counselling standards and on the qualifications required of counsellors[185]. In addition, insured people in receipt of long-term care insurance benefits are legally entitled to receive general care counselling from the long-term care insurance fund or the private insurance company that provides the private compulsory long-term care insurance[186]. Qualified care consultants determine the specific need for help, provide comprehensive advice on the available offers and support the care situation, and, if necessary and on request, they can also draw up a personal care plan. In this context, care support bases (*Pflegestützpunkte*) offering advice and

[181] Section 114a para 1 Social Code Book XI.
[182] Section 114a para 2 Social Code Book XI.
[183] Section 45 para 1 Social Code Book XI.
[184] Section 37 para 3 Social Code Book XI.
[185] Section 37 para 5 Social Code Book XI.
[186] Section 7a Social Code Book XI. The same applies to insured people who are not in receipt of long-term care insurance benefits but have applied for them and clearly are in need of help and counselling. Caregiving relatives and other people , such as volunteer carers, are also entitled to care counselling; this requires the consent of the person with care needs.

support are being set up to provide relevant information, application forms and practical assistance.[187]

Moreover, in 2017, a major reform of care training for LTC professionals (*Pflegeberufereformgesetz*), was undertaken in order to modernise training and thereby make it more attractive. The reform of care training is underpinned by a specific funding system, which ensures adequate funding of training measures and remuneration of trainees.

A shortage of care professionals and poor working conditions at some of the care providers are thought to be relevant factors where quality shortcomings occur. High-quality care requires adequate staffing, in both quantitative and qualitative terms, but meeting the high demand of qualified carers for older people has been a challenge for many years. Consequently, the Federal Government is attempting to increase the attractiveness of LTC for employees (see section 2.3).

There are some economic incentives that reward LTC providers for extra quality-related efforts.[188] Service providers who fail to meet legal obligations for quality assurance run the risk that LTC funds may terminate the contract for service provision[189]. If recipients of care allowances do not make use of LTC counselling, LTC funds are entitled to cut the allowance accordingly.

## 2.3 Employment (workforce and informal carers)

In 2016, the number of LTC workers was 5.1 per 100 of population aged 65 and more (OECD-28 average: 4.9 %), 86.8 % of them were women (Eurostat, 2019). 49.1 % of LTC workers worked part-time. In 2017, the proportion of women among informal daily carers aged 50 and over amounted to 17.0 % (OECD-18: 13.5 %), the proportion of informal carers providing more than 20 hours care per week 15.0 %. Only 6 % of paid LTC staff had a high-level education (OECD-20 average: 21 %), 80 % a medium-level and 14 % a low-level education.[190]

According to German official statistics, around 1.218 million people were employed in LTC in 2019[191]. More than two thirds of the employees (around 84 % women) work part-time[192]. Nevertheless, LTC is characterised by a pronounced lack of LTC professionals. The shortage of LTC staff is generally a major concern for LTC provision in Germany as the number of people in need of LTC increases faster than the number of people employed in LTC. In the second interim report of the project 'Development of a scientifically based procedure for the uniform assessment of personnel requirements in nursing homes according to qualitative and

[187] These are being set up by the health insurance and long-term care insurance funds on the initiative of a federal state. As of 2017, the role of the municipalities for setting up care support bases was strengthened.
[188] Nursing homes that achieve the downgrading of a person in need of care due to their own activities or rehabilitative measures can e.g. receive a bonus payment of EUR [1-9],[1-9]52 from the long-term care insurance fund. The amount must be repaid to the care fund if the person in need of care is again in need of care or is classified in a higher degree of care within six months.
[189] Section 74 Social Code Book XI.
[190] OECD, *Health at a Glance 2019: OECD Indicators*, OECD Publishing, Paris, 2019, p. 235. https://doi.org/10.1787/4dd50c09-en
[191] Statistisches Bundesamt, Pflegestatistik 2020.
[192] Idem

quantitative standards in accordance with § 113c SGB XI' ['*Entwicklung eines wissenschaftlich fundierten Verfahrens zur einheitlichen Bemessung des Personalbedarfs in Pflegeeinrichtungen nach qualitativen und quantitativen Maßstäben gemäß § 113c SGB XI (PeBeM)*'], Rothgang et. al. calculated that by 2030 the additional personnel requirements will equate to approximate 186,000 full-time equivalents[193]. The main reasons for the shortage of LTC professionals are poor working conditions at some care providers and a comparatively low average wage. However, the working conditions and shortages vary considerably between regions and municipalities and, according to projections, they will continue to do so in the decades ahead (Rothgang et al., 2012), mainly due to regional differences in economic development and internal migration. In addition to the increase in the need of LTC due to demographic change, social change, i.e. the individualisation of lifestyles, the increase in female employment, increasing geographical mobility and the declining importance of social networks, is a challenge to the society's potential for providing informal care. The recruitment of a sufficient number of nursing staff is therefore one of the Federal Ministry of Health's most important objectives.

To address these challenges, in 2018 the Federal Ministry of Health in a joint action with the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the Federal Ministry of Labour and Social Affairs initiated the Concerted Action for the Care Workforce (*Konzertierte Aktion Pflege*), bringing together the relevant actors for hospital and long-term care. In 2019, numerous measures were undertaken to improve working and training conditions in the care sector. Five working groups adopted comprehensive measures covering training, personnel management, occupational health and safety and health promotion, innovative care approaches and digitalisation, the recruitment of nursing staff from abroad and remuneration conditions in the care sector. A report on the status of implementation of the measures of the Concerted Action for the Care Workforce has been published in 2020.[194]

Beyond that, following the Care Staff Strengthening Act (*Pflegepersonal-Stärkungsgesetz*) which came into effect on 1 January 2019, up to 13,000 additional posts were created in residential LTC facilities and will be financed by the Statutory Health Insurance (SHI) fund. Moreover, healthcare funds have been obliged to fund workplace health promotion for care workers. The Care Wages Improvement Act (*Pflegelöhneverbesserungsgesetz*) of 2019 created a legal basis to improve wage conditions for care workers. As a consequence, minimum wages for qualified care workers have been introduced and the minimum wage for nursing assistance staff were raised (and previously existing regional differences were aligned). Apart from that, the training for LTC professionals has been modernised in order to make it more attractive (see section 2.2).

Additionally, the Federal Government has intensified its attempts to recruit LTC professionals abroad, mainly from Central and Eastern European and Asian countries. In

[193] Rothgang et al., *Zweiter Zwischenbericht des Projekts 'Entwicklung eines wissenschaftlich fundierten Verfahrens zur einheitlichen Bemessung des Personalbedarfs in Pflegeeinrichtungen nach qualitativen und quantitativen Maßstäben gemäß § 113c SGB XI (PeBeM)*, Bremen, 2020, p. 328. https://www.gs-qsa-pflege.de/wp-content/uploads/2020/02/2.-Zwischenbericht-Personalbemessung- %C2 %A7-113c-SGB-XI.pdf

[194] https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Pflege/Berichte/2020-12-09_Umsetzungsbericht_KAP_barrierefrei.pdf

2019, agreements on the recruitment of LTC professionals have been reached with Mexico, the Philippines and Kosovo. Moreover, a German Agency for Health and Care Professionals (*Deutsche Fachkräfteagentur für Gesundheits- und Pflegeberufe*) has been set up to support LTC facilities in recruiting LTC staff. In order to facilitate reconciling care and work needs, employees are legally entitled, regardless of status, to reduce their working hours to some extent (see section 1.3).

In summary, the Federal Government is pursuing numerous initiatives in this area, many of which are moving in the right direction. Nevertheless, it is doubtful whether they will be sufficient to tackle the shortage of LTC professionals. What is needed is far-reaching improvements in working conditions and a very substantial increase in salaries. The Federal Government has addressed challenges through the Concerted Action for the Care Workforce (see above). Recruitment attempts abroad will be able to make at most a small contribution to solving the problem, quite apart from the fact that they are transferring staffing problems to the countries where workers come from. Nevertheless, as mentioned above (see section 1.4), the majority of people in need of care are cared for by informal carers, mostly female family members.

German LTCI offers a variety of help and benefits for informal carers. In addition to financial support (nursing allowance), social security coverage, and options for stand-in care (if the family caregivers fall sick or are on holiday), LTCI and are legally obliged to provide training courses for family caregivers. In addition, counselling consultation visits are provided in the home of those in receipt of the nursing allowance. People needing care who are being cared for at home are entitled to receive a relief amount of up to EUR 125 per month (in total EUR 1500 per year) which can also be used to obtain everyday support services (which must be recognised by the responsible state authority in accordance with the relevant state law).

## 2.4 Financial sustainability

In 2019, public spending on LTC amounted to 1.6 % of GDP. In the light of demographic change and growing need, as well, the European Commission expects public spending on LTC to grow to 1.7 % by 2030 and to 1.9 % by 2050 (reference scenario).[195] According to the risk scenario, based on unfavourable assumptions, it might even increase up to 1.9 % by 2030 and to 2.8 % by 2050. Over this period, the share of public spending on residential care and of home care are expected to slightly increase from 35.7 % to 37.0 % (2030) and 39.3 % (2050) and from 23.5 % to 23.6 % (2030) and 24.1 % (2050) of total LTC public spending respectively, while the share of cash benefits is expected to decrease from 40.8 % to 39.4 % (2030) and 36.5 % (2050)[196].

According to most recent German statistics, total expenditure on statutory LTCI amounted to EUR 41.3 billion in 2018[197]. There are no tax-financed federal subsidies in the statutory

[195] European Commission, 'The 2018 Ageing Report', *Institutional Paper* 079, Publications Office of the European Union, Luxembourg, 2018. https://ec.europa.eu/info/sites/info/files/economy-finance/ip079_en.pdf
[196] 2021 Ageing Report.
[197] Bundesministerium für Gesundheit, 2020c.

LTCI. Expenditure on social assistance grants for LTC totalled 4.0 billion[198]. Statutory LTCI expenditure has increased steadily in recent years, significantly in 2017, due to the considerable extension of benefits. The LTCI contribution rate rose between 1995 and 2020 from 1.7 % to 3.05 % (3.30 % for the childless) of gross pay. All involved assume that contributions to LTCI will continue to rise in the coming decades. For the years 2020 and 2021 the so-called 'Sozialgarantie 2021' will prevent an increase of all social contributions to an amount of over 40 % of an employee's salary. The most important drivers of this development are the growing number of people in need of LTC, the relative or absolute decline in the number of people in employment and the threat of a reduction in informal LTC with a simultaneous increase in the number of people cared for in residential homes. In Germany, the willingness to provide informal care is well below the EU-27 average[199] and is expected to decline further. This is due not only to social change, but also to the decline in the number of 'young olds' aged between 60 and 75 with a simultaneous sharp increase in the number of people aged 80 and over from 2030 onwards[200]. Thus, the share of expenditure for LTC in residential homes and for benefits in kind is expected to increase in the decades ahead. However, good macroeconomic performance can help to alleviate the pressure on contribution rates, as was the case over the past decade.

The favourable macroeconomic conditions in Germany have had a positive impact on the evolution of contribution revenues. Due to the new legislation coming into force (see above), 2017 saw an extraordinary increase in expenditure to EUR 35.54 billion[201].

Recent legislation, in so far as it is intended to contain costs, has sought to facilitate the provision of informal care and offer incentives for providers. However, as there are no reporting requirements for short-term absences from work or for work releases under the Caregiver Leave Act and the Family Caregiver Leave Act, there are no official figures available on the extent to which these are actually taken up. In 2017, the terms 'caregiver leave' and 'family caregiver leave' were included for the first time in the micro-census questionnaire. After assessing the results, the Federal Statistical Office estimates the total number of people who took caregiver leave or family caregiver leave in 2018 at approximately 80,000. Take-up of caregiver allowance for short-term absence from work amounts to between 9000 and 13,000 recipients per year. Looking at take up of financial support for employees in the form of interest-free loans, figures show that the take-up was far below the expectations set out in the draft legislation.

Achieving financial sustainability is linked with another characteristic of the German LTCI system, namely the divide between statutory and private LTCI. The dual LTCI system allows people with, on average, higher incomes and lower health risks (with demand for LTC occurring usually later in life) not to contribute to the collective financing of statutory LTCI. A unitary people's LTCI would reduce contribution rates for employers and employees,

[198] Statistisches Bundesamt, 2020a.
[199] Eurostat, 2019, p. 153.
[200] Statistisches Bundesamt, 2019.
[201] Bundesministerium für Gesundheit, 2020c.

particularly if it went hand in hand with the raising or even the abolition of the LTCI income threshold for contribution assessment.[202]

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

The right to benefits under LTC insurance applies regardless of the age of the person concerned. Thus children eligible for LTC are in principle subject to the same legal provisions as older people. In addition to home care, they can be accommodated in inpatient homes for people with disabilities, run by the Disability Assistance Association. Infants up to the age of 18 months are generally classified one care level higher. When the medical review board assesses the need of these children, it is often difficult to distinguish them from the expenses that would also be incurred in the care of a child without disabilities. In addition, it is not always easy to clarify which cost units are responsible in each case. Challenges relate in particular to reducing the burden on parents trying to care for their children at home and defining more clearly the responsibilities for financial support.

# 3 REFORM OBJECTIVES AND TRENDS

In recent years, the legislature has introduced numerous reforms and initiatives to further improve long-term care infrastructure and provisions of long-term care insurance.

**Access and affordability**

- With effect from 2017, the legal entitlement to LTC benefits and the categories of people entitled to LTC benefits have been extended considerably and the assessment of need changed extensively. This reform, the Second Care Strengthening Act (*Zweites Pflegestärkungsgesetz*) adopted in 2015, has improved access to care particularly for people suffering from dementia.
- With effect from 2020, the 'Relatives' Burden Reducing Act' (*Angehörigenentlastungsgesetz*), adopted in 2019, exempted the children of people in need of care from the obligation to cover the remaining costs of care, provided they earn less than EUR 100,000.

**Quality**

- Since 2008, the Review Boards of statutory and private LTC have gradually been given stronger powers to monitor accredited LTC providers' compliance with the legal requirements for care quality, including inspections of accredited residential homes without prior warning.

[202] Rothgang, H. and Domhoff, D., *Beitragssatzeffekte und Verteilungswirkungen der Einführung einer 'Solidarischen Gesundheits- und Pflegeversicherung'*, Universität Bremen, Bremen, 2017.

- The Care Professions Reform Act (*Pflegeberufegesetz*), adopted in 2017, aimed at modernising care training including training for LTC professionals in order to improve LTC quality and make LTC more attractive.

**Employment**

- Several measures have been introduced with the aim of raising pay in LTC. For example, more home care service providers are to be made subject to collective agreements, stipulated by the **Care Staff Strengthening Act** (*Pflegepersonal-Stärkungsgesetz*) in 2018.
- Adopted by the **Care Staff Strengthening Act** (*Pflegepersonal-Stärkungsgesetz*) in 2018, some 13,000 additional posts for LTC professionals will be created in residential homes. Costs have to be borne by the statutory health insurance funds.
- The Federal Government has introduced a legal basis to improve wage conditions for care workers (*Pflegelöhneverbesserungsgesetz*) and has intensified its attempts to recruit LTC professionals from abroad, e.g. by concluding agreements on the recruitment of LTC professionals with Mexico, The Philippines and Kosovo in 2019.

**Financing**

- Contribution rates to LTCI have been raised considerably by legislation adopted between 2008 and 2018 up to 3.05 % and 3.30 % for the childless in 2020, mainly due to the extension of benefits.
- Numerous reforms, adopted between 2008 and 2019, have extended benefits in order to facilitate and provide incentives for informal care in order to contain long- and medium-term LTC costs.

In recent months, long-term care has been the subject of intense legislation, all of which was related to the management of the COVID-19 pandemic. This legislation covered a wide range of aspects. The most important of these include:

- Visits to residential homes were restricted in order to protect residents and employees and to contain the spread of COVID-19. These restrictions were implemented differently in the Länder and have been carefully relaxed since May 2020.
- In residential homes and home care services, all people (including employees) can be tested regardless of whether COVID-19 infections have occurred. COVID-19 or antibody tests will in future be paid for by the SHI funds, even if someone does not show any symptoms.
- Employees in LTC will receive a one-off COVID-19 premium of up to EUR 1000 in 2020. The Länder and/or the employers in LTC can top up the bonus by a further EUR 500, which is tax-free.
- Quality checks in residential homes and advisory visits in home care are suspended for a limited period in order to relieve LTC facilities and professionals of bureaucracy and limit the number of contacts.

- Providers of home care and residential care will be reimbursed straightaway on application for extraordinary, COVID-19-related expenses or losses of income and revenue via the LTCI system.
- Various measures to stabilise at-home care and to offer flexible solutions to COVID-19-related supply shortages.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

In order to meet the challenges outlined above, the author offers the following recommendations for long-term care policy in Germany:

- The number of LTC professionals must be increased considerably. In order to achieve this goal, there is an urgent need for a substantial increase in LTC wages and a significant improvement in working conditions. An important tool for improving working conditions is the development and application of an appropriate personnel assessment procedure.
- LTC is financed in such a way as to entail considerable costs for those in need of care. A financing reform should reduce or eliminate this private co-payments.
- Quality assurance in LTC should be further strengthened. It is also very important to ensure the provision of advice to relatives providing care. However, the quality of LTC also depends crucially on the recruitment of a sufficient number of nursing staff and their training.
- A unitary people's LTCI would reduce contribution rates for employers and employees, particularly if it went hand in hand with an increase in or even the abolition of the LTCI income threshold for contribution assessment.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 82.2 | 83.0 | 83.5 | 82.7 |
| Old-age dependency ratio, 2019 | | 30.4 | 33.2 | 42.1 | 48.3 |
| Population 65+ (in millions), 2019 | Total | 16.5 | 17.9 | 21.2 | 23.2 |
| | Women | 9.6 | 10.1 | 11.7 | 12.8 |
| | Men | 6.9 | 7.8 | 9.5 | 10.4 |
| Share of 65+ in population (%), 2019 | | 20.1 | 21.5 | 25.4 | 28.0 |
| Share of 75+ in population (%), 2019 | | 8.5 | 11.4 | 12.1 | 16.9 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.5* | 19.9 | | |
| | Women | 20.9* | 21.4 | 22.5 | 24.6 |
| | Men | 17.8* | 18.3 | 19.5 | 21.5 |
| Healthy life years at the age of 65, 2018 | Total | 7.1* | 11.9 | | |
| | Women | 7.1* | 12.2 | | |
| | Men | 6.9* | 11.5 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 5,794.5 | 6,020.1 | 6,594.7 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 2,964.1 | 3,418.8 | 4,234.4 |
| | Women | | 1,923.6 | 2,155.3 | 2,727.7 |
| | Men | | 1,040.5 | 1,263.5 | 1,506.7 |
| Share of potential dependants in total population (%), 2019 | | | 7.9 | 8.1 | 8.9 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 18.5 | 18.3 | 20.7 |
| Share of population 65+ in need of LTC** (%), 2019* | | 15.2 | - | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 4.3 | 4.3 | 5.3 |
| Share of population 65+ receiving care at home (%), 2019 | | | 3.6 | 3.4 | 4.1 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 11.3 | 10.8 | 12.9 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 42.5 | 42.1 | 45.4 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 61.0 | 59.0 | 62.2 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 72.1 | - | | |
| | Women | 73.8 | - | | |
| | Men | 68.4 | - | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 6.3 | - | | |
| | Women | 7.9 | - | | |
| | Men | 4.2 | - | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 19.2 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 3.8 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | - | 1,152.2 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 4.5 | 5.1 | | |
| | % Women | | 86.8 | | |
| Share of population providing informal care (%), 2016 | Total | | 6.8 | | |
| | Women | | 8.4 | | |
| | Men | | 5.1 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 15.0 | | |
| | Women | | 15.8 | | |
| | Men | | 13.7 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.4 | 1.6 | 1.7 | 1.9 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.4 | 1.6 | 1.9 | 2.8 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 39.3 | 35.7 | 37.0 | 39.3 |
| Public spending on home care as % of total LTC public spending, 2019 | 29.7 | 23.5 | 23.6 | 24.1 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 31.0 | 40.8 | 39.4 | 36.5 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 1.2 | 1.5 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.5 | 0.5 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# ESTONIA

*Highlights*

- Estonia is a country with an ageing and declining population. At the same time, the **life expectancy of people at age 65 has increased** reaching 18.6 years in 2018. However, life expectancy at age 65 is **shorter** than the EU-27[203] average (20 years in 2018)**.**
- Given the growing care burden and the need for ancillary care due to the ageing population, **the demand for supportive services (e.g. social care) and high-quality long-term care** (LTC) facilities will increase in the future.
- One major problem is the **fragmentation of the systems** involved and the fact that **people might not be able to get appropriate help at the right time.** Therefore, the integration of systems and the development of people-centred policies are important.
- **The availability of LTC services** now often also depend on the family's financial capabilities and the services available in the area. There are no common national standards for services and therefore, in addition to availability, the quality of services may vary.
- The aim of setting up an LTC system is **to reduce the care burden on families** so that it is easier for carers to go to work and at the same time provide better support for their family. Even though most carers work without payment, informal care involves significant indirect costs. Due to limited access to publicly provided community-based services and the high cost of residential care, many families must use informal care.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

As the number of people in Estonia keeps falling, the working-age population is also decreasing, caused by the negative birth rate as well as emigration. By 2030 there will be 1.3 million people living in Estonia and by 2050 the population will remain at a similar level.[204] As well as decreasing, Estonian population is also ageing. In 2019, life expectancy at the age of 65 was 19.0 years (EU-27 average was 20.2 years) and it was higher for women compared to men (21.1 vs 15.8 years). Healthy life years at 65 are on a similar level for men and women (5.6 vs 5.8 years in 2018), but shorter compared to the EU-27 average (9.8 years for men and 10.0 years for women).[205]

[203] EU-27 refers to the current 27 Member States of the European Union.
[204] Estonian Statistics has projected that by 2030 there will be 1.25 million and by 2040 1.19 million people living in Estonia.
[205] All data used in the text comes from Section 5 'Background Statistics' unless explicitly stated otherwise.

In 2019, 19.8 % of the population was aged 65 or older (0.3 million people) and 9.5 % were aged 75 or older. The share of population aged 65+ increased by 2.3 percentage points (p.p.) compared to 2008. By 2050, 28.2 % of the population will be aged 65 or older and 15.4 % will be aged 75 or older. In 2019, the old-age dependency ratio was 31.0 (EU-27 average was 31.4), but it is projected to reach 49.1 in 2050. The fact that Estonia's population is shrinking and the population is ageing necessitates changes in policy areas. Policies are needed to ensure a sustainable social protection system and an increase in the well-being of the population.[206] Between 2018 and 2050, the number of very old people in the EU-27 is projected to more than double, increasing by about 130 %. To give some idea of the magnitude of this change, the number of people aged 85 years or more is projected to increase from 13.8 million in 2018 to 31.8 million by 2050, while the number of centenarians (people aged 100 years or more) is projected to grow from close to 106,000 in 2018 to more than half a million by 2050.[207]

## 1.2 Governance and financial arrangements

In terms of financing, fragmentation arises from the separation of funding streams between the state and local government. Long-term health care services, such as residential and home-based nursing care, are financed at the state level by the Estonian Health Insurance Fund (EHIF). In turn, long-term social care services, such as help with daily activities in the home or in social welfare institutions, are financed primarily through local government taxes with limited equalisation payments from the state for lower-income municipalities. Other social care services such as special care services and childcare services are financed directly by the state.[208]

The organisation of LTC in Estonia is divided between two systems - the local and the state system. Local government is responsible for organising local welfare services and benefits, while the state is responsible for organising state level benefits, rehabilitation services and special care services for people with special mental needs. In the field of healthcare, the state is responsible for homecare (including home nursing, home supportive care for cancer patients, geriatric assessment) and residential nursing care.[209] Social protection measures can be grouped into welfare services and social security. Welfare is a system of procedures aimed at securing various freedoms of the people and at creating better opportunities for economic development through human resource development. At the same time, it increases social inclusion, by preventing and reducing poverty and social exclusion more widely and more effectively. Welfare-related instruments (operations) can be both welfare allowances, and welfare services. As services are the responsibility of different systems, it is also difficult to integrate them.

[206] Sotsiaalministeerium, *Heaolu Arengukava 2016 - 2020*, 2016.
[207] Eurostat, *Ageing Europe: Looking at the Lives of Older People in the EU,* Publications Office of the European Union, Luxembourg, 2019.
[208] Paat-Ahi, G. and Masso M., *ESPN Thematic Report on Challenges in Long-Term Care Estonia*, European Social Policy Network (ESPN), European Commission, Brussels, 2018.
[209] Sotsiaalministeerium, 2016.

Long-term care is either formal or informal in Estonia. Formal care is provided by either public or private bodies that meet the required standards. Informal care can be considered the backbone of the current social LTC system in Estonia and informal carers are usually related to the person in need of care.[210] According to the Estonian Social Survey, approximately 35,100 women and 24,500 men have an obligation to provide assistance or care to a family member[211]. About 6500 of the family members assisted or cared for were 0-17 years old, about 20,300 18-64 years old and about 32,800 aged 65 or older. Approximately 26,300 people cared for their adult family members for less than 10 hours a week, 10,400 people for 10 to 19 hours a week and 22,800 people for 20 hours or more a week[212].

The provision of social welfare services is financed from the state budget and local government budgets, and in the case of several services, people pay a co-payment. In addition, the development of social welfare and the improvement of aid measures are supported by European Union structural funds.

The lack of uniform guidelines and precise criteria for local government social services, fragmented and uncoordinated service provision and insufficient funding have led to inequalities in treatment for people with similar needs. The bases and amount of care allowance, the package of services provided, and the circle of service recipients differ across the country. Due to the uneven development of regions, the economic capacity of local governments differs, as it depends on how much, what services and for whom they can finance. Insufficient funding for services has also been caused by policy choices made at the local government level, where social welfare is not prioritised.

A comprehensive long-term care concept together with proposals for renewing the state-local government financing model was approved by Cabinet of Ministers on 30 January 2020. The organisation of LTC care services will be done in state-local government partnership. The state will take more responsibility to develop and provide those LTC services, which are not reasonable to develop and provide on local level. The new model is to be implemented from 2022. Currently the proposals for legislative amendments are being prepared.

Until now, social protection has not been a priority area for local governments. Although the revenue base of local governments has increased year-on-year, expenditure on social protection has not increased at the same rate. At the same time, there has been an increase in the number of institutional services that are largely paid for by the individual (e.g. in the case of out-of-home care, people's own contributions accounted for about 78 % of total costs in 2017[213]) or largely organised and financed by public funds (special care services).

## 1.3 Social protection provisions

The need for personal assistance increases with age, so older people benefit most from services offered at home. There is no detailed assessment of operational capacity and coping

[210] World Bank, *Reducing the Burden of Care in Estonia*, 2017.
[211] Considering only care and assistance due to the age/long-term health problem/disability of the person being cared for.
[212] Statistics Estonia, (2019). Estonian Social Survey.
[213] Riigikontroll, *Riigi ülesannete rahastamine Euroopa Liidu toetustest Kas riik on teinud ettevalmistusi Euroopa Liidu toetusraha vähenemiseks pärast aastat 2020?*, 2017.

skills at the local government level when assessing the need for assistance. The person's need for assistance is identified by the sponsor and organiser of the service and the systematic and structured collection of the basic material needed for planning the social welfare assistance. The organiser of the service can choose which activities will maintain or improve a person's quality of life and refer the person to the provider of that measure (basic support). Some examples of assessment tool questions would be determining whether the person is able to communicate independently with other people, create new relationships or maintain existing ones; whether the person can independently take care of their physical health and use health care services; whether the person can move independently at home; and whether the person is able to eat independently and carry out related activities.

The primary task of local government in assisting a person is to assess comprehensively to what extent the person who has approached needs help. The same must be done if the information about the person in need of help reaches the local government in another way. In this case, it must also be determined whether the person wants help themselves. Therefore, the legislator has given each local government a legal obligation to establish by a procedure for granting social welfare assistance, so that it is clear for everyone what assistance they are entitled to and whether they are entitled to receive it from the rural municipality or the city.

If the local government has the necessary service providers and the person in need can cover the costs, the local government's obligation may be limited to identifying suitable assistance. However, if there is no suitable service provider or the person is unable to cover the costs, the local government must find a service provider or offer the service itself and, if necessary, also contribute to the cost.

As a rule, everyone is responsible for dealing with their own and their family's social risks. If a person cannot cope alone, the local government has an obligation to provide help in addition to the state. This ensures that everyone can enjoy the fundamental rights and freedoms guaranteed by law.[214]

Residential institutions provide general care services outside the home, the service is provided to people who, because they need assistance and care, are unable to live independently and whose livelihood cannot be ensured in any other way. Most of the users of the service are older people in need of constant care. The general care service is financed mainly by the people themselves and / or their family members and / or partly by local government (for example, if there are no children or the children are insolvent).

Upon the provision of social welfare assistance, the efficiency of implementation of measures from the viewpoint of the person in need of assistance and, if necessary, from the viewpoint of the family and community shall be taken as the basis. If a person, in order to improve their ability to cope independently, needs long-term and diverse assistance which also includes the need to co-ordinate the co-operation between several organisations, the principle of case management shall be used (in particular, the person's needs are identified and then the possible services provided).

[214] Õiguskantsler, *Sotsiaalteenused Kohalikus Omavalitsuses*, 2016.

Local government will establish the procedure for the provision of social welfare assistance which shall contain at least the description and financing of social services and benefits and the conditions and procedure for applying for social services and benefits. Local government may organise social services and pay supplementary social benefits from a local government budget under the conditions and according to the procedure established by the local government. Local government shall identify the need for assistance of a person who requests help and determine what that should be. Identifying the need for assistance shall be based on the person's situation, taking into account the circumstances affecting their ability to cope and participate in social life, including: the ability for the person to operate in their physical and social environment. A fee may be charged for the provision of social services. Individual local governments establish the conditions and amount of the fee charged for social services provided by themselves. The charging of a fee is decided by the government which pays for or provides the service. Both the conditions for the provision of services and the payment of fees can differ significantly between different local governments. It depends on the services provided and the capacity of the local government.

Care and service needs assessment practices vary widely across institutions and sectors, and there is no common standardised assessment framework for social and health care.

## 1.4 Supply of services

Long-term care services can be obtained from the local government, the health care system, and the Social Insurance Board. Unfortunately, Estonia has not gone so far as to unify the assessment of those in need. All the different parties make their own assessment and it is often not known that another body has already assessed the person. The services organised by local governments are general care services provided outside the home, personal assistant service, home service, support person service, childcare service for a child with disabilities and day care service. The services financed from the state budget through the Social Insurance Board are special residential care services, support care services and rehabilitation services. The services financed through the Estonian Health Insurance Fund are nursing care, home nursing, primary and special care[215]. In the future, these three will be integrated into a single long-term care system.[216] In addition to care in nursing homes, Estonia offers a home service that ensures the care of people in their own homes.

As of 2019, there are 174 general care homes in Estonia with 9709 places, most of which are owned by local governments or the private sector. In some cases, the municipality also helps to manage the general care home, but usually a fee is still charged. General care home placement fees range from EUR 467-1307 per month, depending on the condition of the person in need of care and the services and the level of comfort provided. In general, fees are higher around the capital, while lower in rural areas.[217]

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[215] Lai T, Habicht T, Kahur K, Reinap M, Kiivet R, van Ginneken E., 'Estonia: Health system review', *Health Systems in Transition*, 15(6): pp. 1-196., 2013.
[216] Riigikantselei, *Poliitikasuunised Eesti Pikaajalise Hoolduse Süsteemi Tõhustamiseks Ja Pereliikmete Hoolduskoormuse Vähendamiseks. Hoolduskoormuse Vähendamise Rakkerühma Lõpparuanne*'.
[217] MoSA (Ministry of Social Affairs), 'General Care Services. Statistics', 2020. https://www.sm.ee/et/uldhooldusteenust-pakkuvad-hoolekandeasutused.

Formal LTC services and related support services are provided by both the health and social welfare systems. The goal of long-term healthcare services is for the person to improve, maintain or regain health, or to adjust to a health condition. The goal of social LTC services is to maintain, regain or improve capabilities in day-to-day life, while either living at home independently, at home with domestic care or in residential care.[218]

The limited supply of home-based services[219] for the older people has led to a growing demand for general care homes. Most older people finance social services from their state-provided pension, which is often not enough to cover the costs of even the least expensive general care home. The limited supply of home-based services for older people results in growing demand for general care home services as the population ages, though unit costs of home-based services are much lower. The usage of general care home services increases year on year, and from 2014 to 2019 the number of clients grew almost by a third. Public expenditure on this service during the five-year period increased by 33.2 %, while out-of-pocket (OOP) spending went up by 89.0 %, comprising 78.3 % of the total expenditure[220]. Given that the average monthly payment for general care home services considerably exceeds the average old-age pension, usage is limited by the income level of the older person (and of their relatives).[221]

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Long-term care services are provided by both health and social care institutions (hospitals, residential care) and at home (home nursing service, home service). People are cared for by formal carers (nurses, carers) or informal carers (spouses, children or parents, other relatives).[222] In 2019, 10.1 % of the population aged 65+ received care in an institution, 20.2 % received care at home and 2.9 % received LTC cash benefits. In 2019, the proportion of the population 65+ who used home care services in the previous 12 months was 3.3 %. Due to the lack of public funding, coverage of services is insufficient and unequal. There is a lack of nursing beds in long-term care. In 2017, there were 871 long-term care beds per 100,000 inhabitants. Access to nursing care is uneven across regions, partly due to a shortage of nurses. In the social field, long-term care coverage depends on the ability of local governments to provide social benefits and services and depends to a large extent on the amounts provided for this purpose in the budget. Although local governments must comply

[218] Paat, G. and Merilain, M., *Long-Term Care in Estonia – Enepri*, 2009. http://enepri.eu/publications/long-term-care-in-estonia/

[219] This is intended for people who need assistance in their home, i.e. assistance in activities that are essential for living at home, but which the person is not able to perform without personal assistance, for instance bringing firewood or water inside, assistance in cooking, cleaning, washing, etc. The person may be assisted within the framework of domestic services also outside the home if this is necessary for coping, for instance bringing food from the shop, taking the person to the doctor, etc.

[220] MoSA, *General Care Service statistics*, 2020.

[221] Paat-Ahi and Masso M., *ESPN Thematic Report on Challenges in Long-Term Care Estonia*, European Social Policy Network (ESPN), European Commission, Brussels.

[222] Saadi, R., *Hoolekandepoliitika Eesmärgid Ja Võimalikud Abimeetmed. Teel Pikaajalise Hoolduse Süsteemi Poole*, Sotsiaalministeerium, 2018.

with legal obligations when providing long-term care services, they have a high degree of decision-making autonomy in defining their policies, and their ability to provide and fund services varies to large extent.

The main responsibility for funding long-term care services lies with the people themselves, largely due to insufficient public funding of social services. Thus, the availability of services increasingly depends on the ability of the service user to pay, which leads to an increased risk of poverty for those using these services. In recent years, the availability of home-based services for the older people has barely increased, despite the relatively low unit cost of home-based services. The limited supply of home-based services and the increasingly level of complex health conditions have led to a higher demand for general care services. Most older people are covered by a state pension for general care, which is often not enough to pay for even the cheapest care home.

Statistics show that household out-of-pocket payments were 0.3 % of GDP for long-term care health and 0.1 % of GDP for long-term care social in 2018. In 2016, the share of households in need of LTC not using professional homecare services for financial reasons was 39.6 % and 23.6 % didn't use the service because it was not available (EU-27 average 35.7 % and 9.7 %).

There is no national data collection and monitoring framework that would allow an analysis of the level of service provision and quality. Data on social services is largely managed only at the local government level, and although there is a plan that in the future, all local governments will be obligated to enter the data in the national social services and benefits data register (STAR), much of it is still paper-based.

Inefficiencies are exacerbated by the separation of health and social care. Different funding sources and the very clear institutional and professional separation do not encourage these areas to coordinate care and provide services. The separation of fields is also reflected in the parallel provision of similar home and community services (home nursing and personal care services) and residential care (general care homes and hospices). The primary health care system does not centrally coordinate the movement of people between health and social services.[223]

## 2.2 Quality

The coverage of social services organised by local governments in legislation is only general and there are no specific criteria for services (target group, service components, quality requirements). Local governments' own legislation and the organisation of social services vary widely across the country and lead to inequalities in treatment across the country. The lack of more precise criteria means local governments have to provide services on a large scale, for which they do not have enough resources, and has led to the range of recipients of services being limited and other restrictions. In addition, local governments have pointed out that the lack of more precise service criteria creates unreasonable expectations for the content

[223] Lai, A., 'Pikaajalise Hoolduse Olukord Eestis Ja Riigi Väljakutsed Omastehooldajate Koormuse Vähendamisel', No 4, *Sotsiaaltöö*, 2017, pp. 8–14.

and volume of services by the recipients. To ensure equal treatment and equal access, quality and efficiency of services, the World Bank has recommended the establishment of more precise mandatory minimum criteria for municipal social services.[224]

In accordance with the Estonian Social Welfare Act, since 2018 there are quality principles that must be followed in the provision of social services. The Estonian Social Insurance Board has developed between 2018 and 2020 general and service based quality standards and service based guidelines for social services. These guidelines are recommended for service providers, municipalities' supervisors, but do not have legal power.

Social welfare infrastructure has been modernised in recent years. Investments have been made to improve the living conditions of people with special needs. With the support of European Structural Funds, large hospital-like institutions for people with special needs have been reorganised into smaller units and apartments in communities. Investments have been made also into care homes to improve their energy efficiency and establish places for people with dementia.

The lack of harmonised criteria and data collection on the provision of social services and service users in local government does not allow for the national collection of data on the need for services at local government level. This has led to a situation where the state does not have the necessary data on the need of services in local governments for policy making, and it also does not allow local governments to have an overview of the service needs of people living in their territory. This situation is the opposite of a health system with highly developed data exchange and digital systems. In health care, all the patient's diagnoses, treatment, etc. can be seen, but unfortunately it is not possible to link it in any way with the social system. One reason is data compatibility, but also data protection.

There is no comprehensive approach to the issue of human resources and manpower in long-term care. There is a growing need for personal helpers, case managers, supervisors and carers of children with special needs and carers.[225] One of the reasons for the lack of workers is low salaries, but at the same time the work is difficult and requires some training.

## 2.3 Employment (workforce and informal carers)

Provision of LTC can be either formal or informal.[226] Among the political changes, the area of social work is influenced by administrative reform,[227] changes in the Social Welfare Act and ESF funding. Based on the experience so far, experts say that administrative reform does not change the number or need of local government social workers. There is a redistribution of posts in the united local governments, the number of (departmental) managers is expected to decrease and the number of specialists will increase. In larger municipalities, opportunities

[224] Riigikantselei, *Poliitikasuunised Eesti Pikaajalise Hoolduse Süsteemi Tõhustamiseks Ja Pereliikmete Hoolduskoormuse Vähendamiseks. Hoolduskoormuse Vähendamise Rakkerühma Lõpparuanne*.
[225] Urve Mets and Vootele Veldre, 'Tulevikuvaade Tööjõu- Ja Oskuste Vajadusele: TERVISHOID' (Tööjõuvajaduse seire- ja prognoosisüsteem OSKA, 2017).
[226] European Commission, 'Long-Term Care: Need, Use and Expenditure in the EU-27', *Economic Papers* 469, European Commission, Brussels, 2012. https://ec.europa.eu/economy_finance/publications/economic_paper/2012/pdf/ecp469_en.pdf
[227] Rahandusministeerium, *Haldusreform 2017*, 2017.

for specialisation arise. With support from the European Social Fund,[228] support for the development of disability support services will increase in the coming years. The money spent on training and hiring support staff and providing care services means that more people will be involved in working with people with disabilities.

From 2020, it is be mandatory for caregivers to undergo professional training before starting work. A distinction can be made between carers in careers with lower education and previous (similar) unskilled work experience. There is a section of the maintenance staff which has secondary education and previous experience in trade, sales, service work, etc. One third of the care workers are people with secondary or higher education who have previously worked as professionals (e.g. as an accountant) in another field and have now found a challenge in working with people.

According to the statistics of the Ministry of Social Affairs, in 2019 the average wage of a care worker was EUR 838 (60 % of the Estonian average). The median salary of a middle level specialist social worker in 2019 was EUR 1033 and social work manager and counsellor EUR 1304, which is slightly more than the median salary (EUR 1143 in 2019)[229].

There is a growing need for personal assistants, case managers, activity supervisors and home care workers. However, the long-term impact of the time-limited projects financed by the ESF on labour demand is unclear. The state has an obligation to ensure the sustainable provision of the developed services also after the end of the project, but the financial resources for this are limited. Therefore, the provision of services may be difficult, e.g. there is no clear funding for the reform after the end of the ESF period (from 2020) and there are examples where the service could be terminated at the end of the project.[230]

Caregivers (informal) bear a disproportionate care burden. In Estonia, approximately 35,100 women and 24,500 men have an obligation to provide assistance or care to a family member[231], both in terms of care as well as on paying for care services. Due to the care burden, people tend to drop out from the labour market (according to Labour Force Survey database 8000 people are not economically active and 5000 are working part-time) or provide care in addition to full-time work. Caregiver burden and strain can also contribute to the caregiver's own poor health. This situation does not guarantee the human dignity of carers and dependants and, in addition, imposes indirect costs on the state - loss of tax revenue, additional burden on the health care system, financial support for people's livelihoods.

A new care leave form came into force in 2018. Employees can use additional leave (five calendar days per year) to care for an adult family member with a profound disability. The employee has the right to use five working days paid leave in the calendar year to address the special needs of the person with the profound disability. It's possible to take these days one by one or all together. And all close family members mentioned before are eligible to use this additional leave, but only one person at the time. The leave allowance is compensated based

[228] Sotsiaalministeerium, *Struktuurivahendid Sotsiaalvaldkonnas 2014 - 2020*, 2019. https://www.sm.ee/et/struktuurivahendid-sotsiaalvaldkonnas-2014-2020.
[229] Statistics Estonia, (2020), *Ametite kuupalgad*. https://ametipalk.stat.ee/.
[230] Mets and Veldre, 'Tulevikuvaade Tööjõu- Ja Oskuste Vajadusele: TERVISHOID'.
[231] Considering only care and assistance due to the age/long-term health problem/disability of the person being cared for.

on the minimum wage that has been established by the ECA (minimum wage in 2020 is EUR 584).

In Estonia, the number of personal carers at home decreased, while it increased for those working in institutions. Estonia has a larger home-based LTC supply than the other OECD countries: institution-based workers represent less than 30 % of the overall LTC workforce. Preparing patients for examination or treatment is a less common task provided by personal care workers; in Estonia they are not allowed to administer medications. In Estonia, the supply of LTC workers is greater than (or close to) the OECD average, but the tenure of current workers is lower.[232]

In 2016, the number of LTC workers per 100 individuals older than 65 was 5.3 (100 % women). This number is slightly higher than the EU-27 average (which is 3.8). In Estonia, a total of 13.4 % of the population was providing informal care (EU-27 average was 10.3 %). The share of informal carers providing care for more than 20 hours per week was 17.3 % (19.9 % women and 13.8 % men), which is slightly lower than the EU-27 average (22.2 % in total, 24.6 % among women and 18.5 % among men).

The number of long-term care beds has grown significantly over the years: in 2008 there were 582.4 beds per 100,000 inhabitants, by 2016 it had risen to 870.7 beds per 100,000 inhabitants. In 2019, 3.3 % of people over the age of 65 (1.9 % of men and 4.1 % of women) had used home care services.

The number of people in home care has not changed in recent years (2016-2019), staying at between 6300 and 7300 dependants. The number of care workers has tended to decrease slightly in recent years (2008 = 705; 2019 = 694 (-1.6 %).

Based on scientific evidence as well as approved international guidelines and best practices, through the cooperation with people with dementia and their families as well as service providers in the medical and social sector, the Ministry of Social Affairs along with its' partners founded the Dementia Competence Centre (DCC) in September of 2018. The aim of the DCC is to improve the quality of care services and quality of life of people with dementia and their caregivers. The focus areas of the DCC are:

- raising awareness towards a dementia-friendly society;
- facilitating integrated care;
- building support systems for people with dementia and their families; and
- coordinating academic research activities on dementia-related topics and disseminate evidence-based knowledge on best practices.

The DCC provides counselling services and support groups for those with care needs as well as tools and educational trainings for professionals and service providers who are working with people with dementia, and their caregivers.[233]

[232] OECD, 'Who Cares? Attracting and Retaining Care Workers for the Elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en.
[233] For more information, please see the DCC webpage: https://eludementsusega.ee/.

In 2019, the social welfare unit was established in the Social Insurance Board. The unit provides strategic, operational and case-based counselling for local governments in performing their social welfare tasks. Common workshops, trainings and information seminars are organised to raise awareness among local municipalities and service providers.

## 2.4 Financial sustainability

Spending on LTC is highly likely to increase as the population ages, but the extent of the increase will depend on factors such as changes in health status and the impact of declining fertility levels on the availability of informal carers. The effects of ageing on health care spending are less clear. Changes in health status are a critical factor. Ultimately, however, the most important factor may be the speed and extent of the policy response to ageing, particularly when we consider that improved health among older people would not only lower spending on health and long-term care, but would also boost health sector revenues by allowing older people to stay in the labour market longer.[234]

LTC spending has seen the highest growth across the various functions and is expected to rise further in the coming years. Population ageing leads to more people needing ongoing health and social care; rising incomes increase expectations on the quality of life in old age; the supply of informal care is potentially shrinking (particularly related to the decrease in labour); and productivity gains are difficult to achieve in such a labour-intensive sector. All these factors create upward pressures on spending.[235]

In Estonia, the public spending on residential care was 52.7 % (EU-27 average 48.1 %) of total LTC public spending in 2019 and is projected to reach 53.6 % by 2050. Public spending on home care was 42.7 % (EU-27 average 25.5 %) of total spending and is projected to reach 42.2 by 2050.

Public spending on LTC was 0.4 % of GDP in 2019 and public spending on cash benefits was 4.6 % of total LTC public spending (EU-27 averages 1.7 % and 26.4 %). The forecast shows that LTC spending as a percentage of GDP will increase over the years, both according to the reference scenario and the risk scenario. However, it will be higher with the risk scenario – in Estonia, LTC spending in 2050 will be 2.1 % of GDP according to the risk scenario and 0.6 % according to the reference scenario. At the same time public spending on cash benefits will decrease from 4.6 % of total LTC public spending in 2019 to 4.2 % in 2050. The number of potentially dependent people was approximately 147,000 in 2019 (11.1 % of total population), but according to the forecast it will increase to 170,000 (13.5 % of total population) by 2050. On average in the EU-27, the share of potentially dependent people was 7 % in 2019. In Estonia, the share of the population 65+ in need of LTC, having at least one severe difficulty in personal care and/or household activities was 26.6 % in 2019.

[234] Sarah Thompson et al., 'Responding to the Challenge of Financial Sustainability in Estonia's Health System' (WHO, 2010).
[235] OECD, *Health at a Glance 2019: OECD Indicators,* OECD Publishing, Paris, 2019. https://www.oecd-ilibrary.org/social-issues-migration-health/health-at-a-glance-2019_4dd50c09-en

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Long-term care for working age people with mental illnesses and intellectual disabilities is also in need of reform and additional financing. The services, which include both supportive day care as well as institutional 24-hour care services, are organised by the state and mainly financed from the state budget and users' co-payments. There are around 50,000 people with mental health issues in Estonia, and the number is increasing by around 5 % each year.[236] The main issue has been the lack of care places which has caused waiting lists of over a year. In recent years, several changes to the system have been made and planned. From 2006, the deinstitutionalisation of special care services has been planned. The initial start was rather slow, but considerable progress has been made, and additional finances have been allocated to the system, increasing the number of places and introducing new services (e.g. interval services).[237] Since 2017, a new person-oriented special care service model has been developed and tested. With the new model, the responsibility of evaluating the situation and needs of and organising suitable services for a person in need is shifted from the state to the local governments. In addition, the support and services provided to the person are a mix of different components chosen specifically according to their needs as opposed to the current system where universal services are provided. However, although several steps have been taken to improve the system, the issue of long waiting lists remains. This issue is especially acute when it comes to institutional 24-hour services. At the end of March 2020, there were a total of 2147 such service places in Estonia; 18 of these places were vacant. At the same time, there were 868 people on the waiting list for these services.[238]

A new flexible respite care service was launched in 2018 for people with mental disabilities. The aim of this service is to give family members free time or participate in the labour market.

# 3 REFORM OBJECTIVES AND TRENDS

In Estonia, there are no recently completed reforms on LTC, but there are several new planned reforms or other ongoing activities coordinated at the national level. The following table summarises them briefly.

***Planned reforms and ongoing legislative process and debates***

***New LTC reform[239] (planned 2021)***

*The action program of the Government of the Republic for 2016-2019 provided for the submission to the Government of the Republic of a concept on the planned changes in the LTC system. The aim of*

[236] Krais-Leosk, M., Erihoolekandes on nii muresid kui ka rõõmustavaid arenguid, *Sotsiaaltöö,* 2/2018, 2018, pp. 29-32.
[237] Read more: Kadarik, I. and Masso, M., 'Recent progress in the process of deinstitutionalisation of special care services in Estonia', *ESPN Flash Report* 2018/49, European Commission, Brussels, 2018. https://ec.europa.eu/social/BlobServlet?docId=19977 and langId=en.
[238] Sotsiaalkindlustusamet, *Erihoolekandeteenuste järjekord,* 2020. https://www.sotsiaalkindlustusamet.ee/et/puue-ja-hoolekanne/erihoolekandeteenused#Erihoolekandeteenuste %20j %C3 %A4rjekord.
[239] Sotsiaalministeerium, *Jätkusuutliku Pikaajalise Hoolduse Süsteemi Loomise Ning Hoolduskoormuse Vähendamise Kava. Kiidetud Heaks 6.12.2018 Valitsuskabineti Istungil*, 2018.

*establishing an integrated LTC system is to reduce the care burden and ensure the cross-sectoral provision, availability and quality of human and family-oriented services. The preparation and implementation of the changes will involve partners to provide solutions for the integration of different systems, create a sustainable and cost-effective financing system for the LTC system and develop a legal framework to regulate LTC between the health and social care sectors and responsibilities between the state and local government. According to the current plan, the changes in legislation will be made step-by-step starting from 2021.*

***Care coordination[240] (planned 2021)***

*Coordinated arrangements are needed to reduce the administrative burden on people with care needs and those close to them, and to provide people with appropriate assistance as soon as the need arises and to better collect information on deficiencies. In the period from 01.08.2018 to 31.07.2019, a pilot project on care coordination was implemented in six Estonian regions. Based on its results, discussions with stakeholders and international experience, a uniformly described coordination model is the most appropriate for the Estonian situation, in the implementation of which it is possible to consider regional specificities. The Ministry of Social Affairs, in cooperation with partners, prepared a framework draft document for the nationally implemented coordination model at the end of 2019. With the support of European structural funds, the implementation of the new model will start in 8-12 Estonian regions in 2020. The goal is to develop a detailed plan for the implementation of the coordination model across the country by the end of 2021.*

***Nursing care in institutions[241] (planned 2020)***

*One of the principles of LTC arrangements is that nursing care must be provided to the extent necessary for the person, regardless of whether the person needs this service at home, in a care institution or in a health care institution. To this end, the EHIF developed, as a first and important step, a model for the organisation and financing of nursing care services in care institutions providing general care services outside home, which can be implemented already in 2020. The service is financed based on an agreement with the Estonian Health Insurance Fund, which enters into agreement with a legal person holding an activity license for the provision of nursing services. Like the home nursing service provided at home, the nursing care service for people in care institutions is free of charge.*

***Availability of resources and assessment of the need for assistance[242](partly ongoing the end of 2019)***

*In order to improve the accessibility of benefits and services for people with special needs, Estonia has made several changes to simplify the system and make it easier to access these (e.g. the circle of specialists who identified the need for nursing care expanded; primary proof is no longer required to buy nappies, bandages, absorbent sheets). There is also a review of the aid systems organised through various state agencies and the development of possible amendments together with stakeholders. Now, the organisation of the need for assistance is complicated and inconsistent. To receive assistance, a person with a disability must undergo several assessments at both the state and local government levels. Therefore, many amendments are planned to simplify the system and the*

[240] Kupper, K. and Tarum, H., 'Pikaajalise Hoolduse Süsteemi Tuleb Eestis Muuta', *Sotsiaaltöö Korraldus*, 4, 2019, pp. 8–11.
[241] Kupper and Tarum, 2019.
[242] Kupper and Tarum, 2019.

*assessment of the need. In the future, there is a need to continue to update the principles for assessing the needs of people with disabilities and to reach to a situation in which assistance for people with special needs is integrated into the organisation of long-term care.*

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

In the coming decades, LTC problems will be an increasing challenge in Estonia. The population is ageing unhealthily, the workforce is shrinking, and it is becoming increasingly difficult to help people. Considering future needs and expenditures, Estonia may need to explore new financing models to meet future demands for LTC. Despite a great variety in approaches and coverage levels of public LTC across countries, recent developments suggest that financing models are converging and that there is an increasing moving towards 'targeted universalism'. In addition, many countries are striving to improve the sustainability of funding sources for LTC, with an eye on unburdening the working-age population. Supporting informal caregivers and improving their chances of participating in the labour market is equally critical in the context of Estonia, where informal caregivers will continue to form the backbone of the LTC care system in the short to medium term.[243]

As previously seen, fragmentation of LTC services and decentralisation of responsibilities are also a major problem. The following policy recommendations seem relevant to boost opportunities to reduce fragmentation challenges:

- To reduce fragmentation and duplication, social and health care integration needs to be enhanced to provide more effective care.
- Integration concerns the reduction of legislative and regulatory constraints and the formulation of common objectives, the standardisation of data and reciprocal access to data as well as funding and co-financing in support of service cooperation.
- Coordinated and human-centred care needs to be provided to deliver services and help based on the needs of the individual. To this end, it is first necessary to harmonise the assessment of care needs, to introduce standardised assessment tools and to use information technology to bring together assessments made in different areas and agencies.

[243] Paat-Ahi and Masso, *ESPN Thematic Report on Challenges in Long-Term Care Estonia*, European Social Policy Network (ESPN), European Commission, Brussels, 2018.

# 5 BACKGROUND STATISTICS

| *5.1. Demographics* | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 1.3 | 1.3 | 1.3 | 1.3 |
| Old-age dependency ratio, 2019 | | 25.8 | 31.0 | 37.1 | 49.1 |
| Population 65+ (in millions), 2019 | Total | 0.2 | 0.3 | 0.3 | 0.4 |
| | Women | 0.2 | 0.2 | 0.2 | 0.2 |
| | Men | 0.1 | 0.1 | 0.1 | 0.2 |
| Share of 65+ in population (%), 2019 | | 17.5 | 19.8 | 23.2 | 28.2 |
| Share of 75+ in population (%), 2019 | | 7.5 | 9.5 | 11.5 | 15.4 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 17.4* | 19 | | |
| | Women | 19.5* | 21.1 | 22.4 | 24.6 |
| | Men | 14.3* | 15.8 | 17.6 | 20.2 |
| Healthy life years at the age of 65, 2018 | Total | 5.5* | 5.7 | | |
| | Women | 5.5* | 5.8 | | |
| | Men | 5.3* | 5.6 | | |

**data for 2010*

| *5.2. People in need of LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 147.0 | 158.2 | 170.0 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 85.1 | 98.8 | 118.7 |
| | Women | | 60.4 | 67.5 | 74.5 |
| | Men | | 24.8 | 31.3 | 44.2 |
| Share of potential dependants in total population (%), 2019 | | | 11.1 | 12.1 | 13.5 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 17.4 | 19.3 | 19.4 |
| Share of population 65+ in need of LTC** (%), 2019* | | 27.2 | 26.6 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| *5.3. Access to LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 10.1 | 10.1 | 10.7 |
| Share of population 65+ receiving care at home (%), 2019 | | | 20.2 | 20.2 | 21.3 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 2.9 | 2.9 | 3.1 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 94.1 | 93.6 | 96.1 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 8.9 | 9.0 | 9.4 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 28.7 | 58.4 | | |
| | Women | 31.1 | 58.8 | | |
| | Men | 21.5 | 57.5 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 4.5 | 3.3 | | |
| | Women | 4.6 | 4.1 | | |
| | Men | 4.2 | 1.9 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 39.6 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 23.6 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 828.0 | 870.7 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 6.5 | 5.3 | | |
| | % Women | | 100.0 | | |
| Share of population providing informal care (%), 2016 | Total | | 13.4 | | |
| | Women | | 14.3 | | |
| | Men | | 12.3 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 17.3 | | |
| | Women | | 19.9 | | |
| | Men | | 13.8 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.6 | 0.4 | 0.5 | 0.6 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.6 | 0.4 | 0.7 | 2.1 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 35.3 | 52.7 | 53.0 | 53.6 |
| Public spending on home care as % of total LTC public spending, 2019 | 3.9 | 42.7 | 42.6 | 42.2 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 60.8 | 4.6 | 4.4 | 4.2 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.2 | 0.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | 0.1 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.1 | 0.3 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | 0.0 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# IRELAND

***Highlights***

- There is currently no statutory framework for homecare service provision in Ireland. This means that there is no regulation on who can provide homecare services or in terms of the quality of homecare. There is in addition an over-reliance on informal care in the homecare sector and on residential care as a response to long-term care (LTC) need overall.
- Ireland has significant under-provision of public services for LTC and therefore high unmet need. The homecare sector in particular has not kept up with demand, and Ireland is still trying to undo the effects of the cut-backs that were made as a response to the 2008 recession. The evidence suggests significant regional and social class-based variations in unmet need – underlining inequity and inefficiency.
- Ireland will be challenged also by the size of the projected increase in need, as a more intense period of population ageing sets in.
- The thrust of reform has been to enable and support informal care through income-support benefits (which have become more widely available and made more flexible) and an unpaid carer's leave. Home care service provision is also gradually expanded in coverage. Major structural reforms have been in the pipeline for the last three to four years – specifically the introduction of a statutory basis for and scheme of home care but progress is slow.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

Ireland's population, on the most recent available data, is 4.9 million. It is projected to rise to 5.5 million by 2030 and 6.2 million by 2050.[244]

The ageing of the population puts the Irish LTC system under considerable demographic pressure in terms of a greater demand for LTC and, at the same time, fewer resources – staff and tax money – to secure the future supply of LTC. The statistics paint a picture of a country that has been relatively protected from rapid ageing but one that will face serious ageing-related challenges in the next 20 years. The old-age dependency ratio will rise by 2030 to 27.0 and a very steep 41.9 by 2050. The number of people over the age of 65 now increases by over 20,000 a year.[245] The specificity of Ireland's situation can be appreciated from the fact

[244] All data used in the text comes from Section 5 'Background Statistics' unless explicitly stated otherwise.
[245] Government of Ireland, *Health in Ireland Key Trends 2019*, Government of Ireland, Dublin, 2019.

that the population aged 65+ has grown by 35.2 % since 2009 (compared to an EU-27[246] average increase of 16.5 %) (Government of Ireland, 2019). Among the consequences is a growing share of the population comprised of older people. The estimations of the proportion of those aged 75 and over are 8.3 % and 12.8 % respectively by 2030 and 2050. The number of potential dependants will rise rapidly – up from 245,000 in 2019 to 307,800 in 2030 to 406,600 in 2050. This can be expected to significantly increase demand for LTC.

Life expectancy at the age of 65 overall in Ireland is 20.8 years in 2019, rising by 1.5 years since 2008. Healthy life years at age 65 is 12.9 years in 2018. The usual gender differences prevail – male life expectancy after age 65 is 19.4 years on the latest figures compared to 22.1 for women. However, the gender gap in life expectancy continues to narrow, with the latest available data showing this gap now at its lowest point since the 1950s (Government of Ireland, 2019). Healthy life expectancy at age 65 is rising faster than life expectancy in general – up from 11 years in 2008 to 12.9 on the latest figures (with the increase for women more pronounced than that for men).

## 1.2 Governance and financial arrangements

LTC provision in Ireland is mainly organised in terms of income support on the one hand and health/care service-related provisions on the other. Strongly centralised (especially from a planning perspective), income support is governed by the Department of Social Protection whereas the latter comes under the auspices of the health system (Department of Health and Health Services Executive (HSE)). Home care in Ireland is dominated by informal caregiving, following a family-based structure similar to southern European countries although this has changed rapidly over the last 20 years given steep rises in female employment rates.[247] A further notable characteristic is the lack of a statutory basis for homecare provision. This has been in debate for the last three to four years at least and is in the process of being reformed however (albeit slowly). There is no significant regional differentiation as regards the governance of the LTC system, with policy highly centralised under the auspices of the Department of Health on the one hand and the HSE on the other. There is variation in access to services by region however (to be discussed in section 2.1 below).

In terms of public expenditure on LTC as a percentage of GDP (reference scenario), in 2019 it was 1.3 %, predicted to rise to 1.6 % and 2.4 % in 2030 and 2050 respectively. Irish expenditure goes disproportionately on residential services – the most recent evidence indicates a 55.4 % share for this sector (with predictions that this will remain more or less stable in 2030 and 2050). The resources for LTC are generated through the tax system (apart from those funded privately). The only cost sharing arrangements that prevail are in regard to residential care where access is on an income-tested basis. This is in contrast to home care, which is based on need.

[246] EU-27 refers to the current 27 Member States of the European Union.
[247] Walsh, B., Wren, M-A., Smith, S., Lyons, S., Eighan, J. and Morgenroth, E., 'An Analysis of the Effects on Irish Hospital Care of the Supply of Care Inside and Outside the Hospital', *ESRI Research Series* No 91, September 2019.

## 1.3 Social protection provisions

Three features of Ireland's income support system for care should be noted at the outset: first, Ireland relies almost exclusively on payments to carers (rather than to the person requiring care); secondly, the vast majority of income support is on a means-tested basis; third, there is very limited medical input into the decision to grant the benefit (mainly a letter from a GP indicating need on the part of the cared-for person).[248]

For the purposes of income support, a carer is defined in the regulations governing the 'carer's allowance/benefit' as someone who is living with, or in a position to provide, full-time care and attention to a person in need of care (either for physical and/or mental health reasons) who does not normally live in an institution. To qualify, the carer must also be habitually resident in the state and must be at least 18 years old (16 if it is for the social insurance 'carer's benefit') and not be engaged in employment, self-employment, training or education courses outside the home for more than 18.5 hours a week (increased in January 2020 from 15 hours). Eligibility conditions also pertain to the cared-for person who must be over the age of 16 and so incapacitated as to require full-time care and attention. In the assessment of applications for carers' benefits, a GP's report on the needs of the cared-for person must be included in the application. Social Welfare Inspectors carry out follow-up visits. A carer's payment can also be made to a person caring for someone in receipt of a 'domiciliary care allowance'. The latter is a monthly payment (EUR 309.50) for a child aged under 16 years with a severe disability who requires ongoing care and attention; it is not means tested and is received only upon the determination of the medical assessor of the Department of Employment and Social Affairs. This is in the Irish system an exceptional payment given on behalf of the person requiring care.

There is both a social insurance and a social assistance version of financial payment for carers. The former – known as 'carer's benefit' – is acquired as a right from contributions to pay-related social insurance. There is only EUR 1 difference in weekly value of the 'carer's benefit' and that of the 'carer's allowance' (EUR 220 compared to EUR 219 a week for a carer under 66 years old and caring for one person). The vast majority of carers' payments are made through the means-tested allowance. In a not unrelated characteristic, the recipients are by and large women, underlining a long-term Irish pattern for informal carers to be women with low or no attachment to the labour market. Both payments are paid on a weekly basis. For the purposes of the means-test for the 'carer's allowance', the means taken into account include the applicant's own income as well as that of their spouse, civil partner or cohabitant (with the exception of the home) or an asset that could yield or provide the applicant with an income (for example, an occupational pension or benefits from another country). There is an income disregard or cut-off of EUR 332.50 of gross weekly income for a single person (double for a partnered/married person).

The 'carer's benefit' is time limited and may be claimed as a single continuous period or in any number of separate periods up to a total of 104 weeks. To be eligible the person must be aged at least 16 and under 66 years old. Also applied is a condition of employment for at least

[248] Details of the care recipient's need and medical conditions are required on the application form.

eight weeks in the previous 26-week period for a minimum of 16 hours a week or 32 hours a fortnight and at least 39 weeks of social insurance contributions in the relevant tax year. One must also have (had) to give up work to become a full-time carer.

While historically income support for carers was treated as separate to the rest of the social security system (and certainly separate from social insurance), a trend for at least a decade now is to try and improve demand and take-up. Hence, recipients can avail of activation services once their period of caring ends and it is possible for a carer to receive the 'carer's allowance' on a half-time basis if they are getting other social welfare payments. In effect, they get a half-rate 'carer's allowance'. Among other support measures is allowing two people who share the care to share the 'carer's allowance' (and the annual 'carer's support grant'). The conditions stipulate, though, that care must be shared in an established and regular manner. Those in receipt of 'carer's benefit' and 'carer's allowance' can build up credits for a social insurance contribution.

As well as direct income payments, Ireland also has a 'home carer's tax credit' which is given to married couples or civil partners (who are jointly assessed for tax) where one spouse or civil partner works in the home caring for a dependent person (including caring for a child with a disability). The annual value of the tax allowance is EUR 1600 (the full amount of which is claimable by a carer with an own income of up to EUR 7200 in the relevant tax year). 'Carer's allowance' or 'carer's benefit' are not taken into account when determining the home carer's income but they are taxable income.

An unpaid 'carer's leave' also exists and constitutes a right or entitlement provided one meets the conditions. The Carer's Leave Act 2001[249] made provision for employees to leave their employment temporarily to provide full-time care for someone in demonstrable need of full-time care and attention (as attested to by a GP). The person to be cared for need not necessarily be a family member; providing care for a friend or colleague is also deemed eligible for leave. To be eligible, the person must have been in the continuous employment of the employer from whom the leave is taken for at least 12 months. There is no hours' threshold specified. The leave is for a minimum of 13 weeks up to a maximum of 104 weeks and may be taken in one continuous period of up to 104 weeks or for a number of separate periods not exceeding 104 weeks in total. While the 'carer's leave' is unpaid, it is job protected for the duration of the leave and the leave taker may be eligible for either 'carer's benefit' or 'carer's allowance'. Employment for a maximum of 15 hours a week is allowed for those on 'carer's leave' provided the income from employment or self-employment is less than a weekly income limit set by the department.

There are also some other entitlements including a 'carer's support grant' - an annual payment made to recipients of payments for carers which is paid automatically annually and can be used as the recipient wishes (and not necessarily to buy respite care, as reflected in the recent change of name from the Respite Care Grant). The value is EUR 1700.

[249] http://www.irishstatutebook.ie/2001/en/act/pub/0019/index.html

For the person needing care, the only statutory scheme currently in place in Ireland to provide care to older people is for residential, LTC which is accessed and funded through the Nursing Home Support Scheme (also known as the 'Fair Deal') which is administered by the HSE. Every older citizen can apply to the scheme through their local health office. In order to get accepted on the scheme, there is a care needs assessment (undertaken by professionals). Upon being deemed to have significant care need, the person then undergoes a financial assessment to determine their self-contribution to the cost of care and the corresponding level of state financial assistance. Under the scheme, people make a contribution towards their care of 80 % of their income and up to 22.5 % of the value of their home, if their assets are over a certain limit, for the first three years of their care, and 7.5 % of the value of any assets (which may be deferred and collected from the person's estate). The state pays the balance. The first EUR 36,000 of assets, or EUR 72,000 for a couple, is not counted in the financial assessment. Note that the principal residence will only be included in the financial assessment for the first three years in care. This is known as the 22.5 % or 'three-year cap'. There is an optional Nursing Home Loan element of the scheme. People can choose public, private or voluntary nursing homes under the Nursing Home Support Scheme from a range of approved providers. 'In 2018, the financial support provided by the state towards the cost of long-term residential care amounted to EUR 969 million, supporting around 23,300 people at year-end. Resident contributions totalled a further EUR 343 million.[250]

**Supply of services**

Unlike some other countries – and especially the UK - Ireland has a relatively integrated health and care system. All public health and social care services come under the remit of the HSE and LTC provision is provided either by public provision or subsidy of services offered through a range of community and purely market-based providers. The official policy approach towards LTC in Ireland is 'that older people are recognised, supported and enabled to live independent full lives'. Ironically, though, the thrust of existing provisions and funding is towards residential care; this is a reflection also of Ireland's 'hospital-centric' model of health care.[251]

Use of residential LTC is rising – up 5.6 % since 2015.[252] It is estimated that 80 % of those in residential care are in private nursing homes.[253] As of December 2018, there were 581 nursing homes registered with the Health Information and Quality Authority (HIQA).[254] More than three-quarters of nursing homes in Ireland are private or voluntary (not-for-profit) nursing homes; the remainder are public facilities. According to Nursing Homes Ireland (NHI), the national representative body for private and voluntary nursing homes in Ireland, there are over

[250] https://www.audit.gov.ie/en/find-report/publications/2020/special-report-110-the-nursing-homes-support-scheme-fair-deal-.pdf
[251] Smith, S., Barron, S., Wren, M.-A., Walsh, B., Morgenroth, E., Eighan, J. and Lyons, S. *Geographic Profile of Healthcare Needs and Non-acute Healthcare Supply in Ireland,* ESRI Research Series No. 90, July 2019, ESRI, Dublin, 2019.
[252] Government of Ireland, 2019.
[253] Dáil Éireann debates, Wednesday 12 June 2019, Vol. 983 No 5.
[254] https://www.hiqa.ie/areas-we-work/older-peoples-services

460 private and voluntary nursing homes providing care to over 25,000 people.[255] There are approximately 5000 people resident in public nursing homes.[256]

Flanking the institutional provision are home care services. Home-based care services come mainly under the heading of 'home support service for older people' (formerly known as 'home help service' and 'home care package') and consist of non-medical and usually non-professional assistance to enable people with care needs to remain relatively healthy and capable of living at home.[257] Such services are supplied either by publicly-employed HSE staff, community and voluntary organisations or private sector agencies. They are free of charge, available on the basis of need/incapacity rather than financial or other resources. The recipient gets a choice of provider but if they opt for non-HSE services then they must choose among approved service providers (unless they want to pay privately).

As of the most recent data some 10.1 % of the population aged 65+ used home care services for personal needs in the last 12 months. Public provision is by far the most widespread form of service used – accounting for over 70 % of home care provision in 2015.[258] In that year the State financed 10.46 million home help hours, with an additional estimated 3.86 million hours privately purchased. The State also provided 15,300 home care packages (Wren et al., 2017). The level of homecare provision varies by need but it is important to note that the average HSE home care service provides one hour of care per day- that is 6 hours a week.[259] For comparison, note that there were an estimated 29,000 LTC residents in 2015, with the majority (over 21,000) covered by the Nursing Home Support Scheme (the 'Fair Deal' scheme). These residents used 10.6 million LTC bed days – over twice as many inpatient bed days as in the public and private acute hospitals systems combined (Wren et al., 2017). Note that unlike the Nursing Home Support Scheme, the home support services have no statutory basis which means that there is no statutory entitlement. For this and other reasons, provision nationally is rather patchy, often depending on geographical location and historical financial allocations. The level of regulation and standard setting has been increased over time.

It is estimated that the formal LTC workforce is equivalent to 4 for every 100 people aged 65 and over, compared to 4.1 % of the population (or 195,263 people) as a whole who say that they are informal carers.

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[255] https://nhi.ie/

[256] Pierce, M., *The Impact of COVID-19 on People who Use and Provide Long-Term Care in Ireland and Mitigating Measures.* Country report in LTC covid.org, International Long-Term Care Policy Network, CPEC-LSE, 2020. https://ltccovid.org/wp-content/uploads/2020/04/Update-Report-for-Ireland-on-LTC-and-Covid-19-14.04.2020-final.pdf

[257] Between 2006 and 2018, two separate public home care schemes existed: the 'home care package' (HCP) scheme and the 'home help scheme'. Historically, the home help scheme provided domestic support including assistance with cleaning, cooking and basic household tasks, while the HCP scheme was introduced in 2006 to provide more intensive care to allow for older people, particular those discharged from hospital or from a rehabilitation facility, to be cared for in their own home. While differences between the two schemes existed in the past, in recent years they have provided similar care and support to aid individuals at home and in 2018 were merged into the 'home support scheme'.

[258] Wren, M-A., Keegan, C., Walsh, B., Bergin, A., Eighan, J., Brick, A., Connolly, S., Watson, D. and Banks, J., 'Projections of Demand for Healthcare in Ireland, 2015-2030: First Report from the Hippocrates Model'*, ESRI Research Series,* Dublin, 2017.

[259] Care Alliance Ireland, *Public Provision of Home Care in Ireland Update October 2018*, Care Alliance Ireland, Dublin, 2018.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

A major difficulty encountered in this project is that there is no national dataset that profiles the number, location and catchment population of non-acute services (Smith et al., 2019). Information on the costs is also very difficult to come by.

## 2.1 Access and affordability

Access and affordability challenges are very significant, especially regarding services (as against income support for carers).

Waiting lists are one important indicator – of those already assessed and confirmed as being in need, some 7000 people are estimated to be waiting at the current time.[260] A second indicator is unmet need. Wave 4 of the TILDA survey (the Irish longitudinal study on ageing) carried out in 2016 showed that 16 % of people aged 75 years and older and 14 % of the 65 to 74 year old cohort reported unmet need in the community.[261] As these results are based on the opinion of respondents, they may not accurately reflect the amount of care needed. EU-27 data for 2016 indicates that 22.1 % of households in need of LTC were not using professional homecare services for reasons of availability. The same data shows that 11.3 % of households in need of LTC reported not using professional homecare services for financial reasons. Research suggests that there is a class gradient in service use and accessibility – although the higher social class households had the lowest need of help, they had the highest percentage in receipt of professional home care among those who do need help, at 34 %, compared to only 21 % of those in the lower social class which had the highest level of help needed.[262]

One obvious explanation for unmet need – which a recent comparative research study found to be highest in the liberal welfare state regimes[263] – is supply. There are several aspects to this. First, the home care service is not budgeted for as demand led. Following the approval of a person for homecare services, the HSE will provide homecare services through its own carers or, if they cannot, the contract will be outsourced to a voluntary organisation. This method is reactionary and only attempts to source hours once approved, leading to a situation where there is little planning for future demand of services and, as such, no capacity for any increase in demand.[264] Second, the home care sector was one of the casualties of the cut-backs introduced in Ireland as part of the response to the recession. Such services declined from covering over 55,000 people in 2008 to under 47,000 in 2016.[265] There were two million home help hours fewer in 2017 compared to 2008. Provision has been slow to catch up. For example, by the end of September 2019 (the last date for which evidence is available), 13.3

[260] https://www.thejournal.ie/readme/opinion-the-solution-to-the-trolley-crisis-is-to-make-home-care-a-statutory-right-4377833-Jan2019/
[261] TILDA, *Wellbeing and Health in Ireland Over 50s 2009-2016,* Dublin, 2018.
[262] Grotti, R., Maitre, B. and Watson, D., 'Technical Paper on Social Inclusion and Access to Care Services in Ireland', *Social Inclusion Technical Paper* No 9, Department of Employment Affairs and Social Protection, Dublin, 2019.
[263] Privalko, I., Maitre, B., Watson, D. and Grotti, R., 'Access to Childcare and Home Care Services across Europe', *Social Inclusion Report* No 8, Department of Employment Affairs and Social Protection, Dublin, 2019.
[264] Houses of the Oireachtas, *Joint Committee on Health Report on the Provision of Homecare Services November 2019*, Dublin, 2019.
[265] Farrell, C., *A Fair Deal for Home Care*, PublicPolicy1e, Dublin, 2017

million home support hours were delivered to older people (not including those in receipt of the Intensive Home Care Package).[266] This equates to a total of 47,384 people in receipt of these hours during that period. In 2019, almost EUR 30 million was added to the home support budget, targeting the delivery of 800,000 more hours than the 2018 target.[267]

In addition, there are variations in supply and in assessment procedures geographically. Smith et al (2019) examined the distribution of the annual average number of home care hours per person aged 65 years and over in Ireland in 2014 and found significant geographical variations (Smith et al., 2019). It seems that the rural counties have consistently higher per capita home care hours across all years. But significant differences within administrative units are also observed. Similarly, the absence of legislation has also impacted upon the assessment of eligibility. The assessment of individuals applying for homecare is determined within each administrative area but there is no standardisation of assessment and many inconsistencies are reported to exist between various administrative units regarding eligibility of services.[268]

Unmet need is in part also attributable to the bias in the system towards residential care. As mentioned, approximately 60 % of the budget that supports older people is spent on long-term residential care, effectively catering for only about 4 % of the population aged over 65.[269]

A third contributory factor is bottlenecks in the system. The *Independent Expert Review of Delayed Discharges 2018* found that 90 % of the 8125 delayed discharges in the year 2017-2018 were people aged 65 years or over, with a similar percentage for the previous year.[270] Other work also underlines the relationship between non-acute service provision and hospital care. Analyses carried out explicitly comparing acute hospital stays between 2010-2015 and publicly-financed home care hours between 2012 and 2015 indicate that an increase of 1.5 million hours in home care supply was associated with about 14,700 fewer bed days in residential care per annum, freeing up 40 beds per day (Walsh et al., 2019).

But unmet need also prevails in regard to nursing home care. The review of the Nursing Home Support Scheme, which was undertaken in 2015[271], concluded that, based on prevailing utilisation rates and projected increases in the numbers of older people, there will be a requirement of over 33,000 Nursing Home Support Scheme beds in the system by 2024.

## 2.2 Quality

In regard to the second challenge – quality - since 2008, there have been independent, unannounced inspections of all public, private and voluntary nursing homes. These inspections are carried out by the HIQA and the Authority publishes the results of regular inspections of nursing homes. Since July 2012, a system of approved service providers has been put in place under home support services. The approved providers, appointed under a tender process, must meet a new uniform level of national standards. There are some 35 standards in all, among which are a person-centred approach, autonomy, safeguarding, the

[266] HSE, *HSE Performance Profile, July to September 2019, Quarterly Report*, Dublin, 2019.
[267] Dáil Éireann debates, Wednesday 12 June 2019, vol 983, No 5.
[268] Houses of the Oireachtas, 2019.
[269] Social Justice Ireland, *National Social Monitor 2017*, Social Justice Ireland, Dublin, 2017.
[270] Department of Health, *Irish Expert Review of Delayed Discharges,* Department of Health, Dublin, 2018.
[271] Department of Health, *Review of the Nursing Homes Support Scheme, A Fair Deal*, Department of Health, Dublin, 2015.

promotion of rights and dignity as well as standards in relation to provision and use of resources.[272] This is a first step in an overall plan to raise standards of home care provision. It is planned that home care services will be independently inspected but legislation is required to do so and no date has been announced by when it will be in place. HIQA was initially scheduled to have been established as a regulator of the sector in 2016 but there is still no mechanism for the oversight of homecare services.[273] Providers are monitored through Service Level Agreements (SLAs) with the HSE and are required to provide a range of information in relation to the services they provide. However, the situation remains that home care services in Ireland are unregulated.

However, there are no independent inspections of home care services for older people and indeed no statutory basis to do so at the present time. The plan is to introduce a statutory basis for home care in 2021. As part of this this an inspection regime will be introduced (details unavailable at this stage). While it is generally agreed that HIQA has been a successful model, the challenges to regulation and monitoring in the home care sector are significant. First of all, the difficulties of monitoring and regulating provision in private homes is amplified in Ireland given the scale of such provision. Second, an informal rather than a professional culture prevails around home care in Ireland, making it difficult to treat it as a 'service' rather than 'help and assistance'.

## 2.3 Employment (workforce and informal carers)

In terms of the formal workforce, Ireland has a ratio of 4 LTC workers per 100 population aged 65 and over. This compares to 3.8 for the EU-27. Women make up 87.3 % of the formal care workforce. On the basis of the available evidence from OECD,[274] LTC workers earn on average around 67 % of the average earnings per hour actually worked in the general economy and 38 % of LTC workers have completed higher education. Ireland compares favourably to Germany on both of these statistics.[275] It should also be noted that Ireland is one of the countries with a relatively high proportion of foreign-born people in the care workforce in both nursing and personal care (they represent over 20 % in Ireland, and Austria).[276] However, it does not appear that Ireland has a large undocumented caring sector (as in some other EU-27 Member States).

The 2016 Census found that 4.1% of the total population (195,263) declared that they provided regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability, including problems due to old age.age. Some of these may be claiming income support benefits but many of whom will not. The Census data also indicated that carers provide over 6.6 million hours of care a week (this 2016 figure was an increase of over 5 % on the 2011 Census numbers). As well as the numbers, the Census data also shows

[272] https://www.hiqa.ie/sites/default/files/2017-01/National-Standards-for-Older-People.pdf
[273] Houses of the Oireachtas, 2019.
[274] Cravo Oliveira Hashiguchi, T. and A. Llena-Nozal, 'The effectiveness of social protection for long-term care in old age: Is social protection reducing the risk of poverty associated with care needs?', *OECD Health Working Papers* No 117, OECD Publishing, Paris, 2020. https://doi.org/10.1787/2592f06e-en; OECD, 'Who Cares? Attracting and Retaining Care Workers for the Elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en.
[275] Cravo Oliveira Hashiguchi and Llena-Nozal, 2020, p. 32.
[276] OECD, 2019.

that women are more likely to be carers – some 60 % of the carers are women. One other gender-related point to note is the much heavier workload borne by female as opposed to male carers – it appears that intensive caring is women's work.[277] In general, working age people in Ireland who are caring for dependent relatives will find it very difficult to achieve a work-life balance and public policy provides little support for this. The 'choice' of whether and how to care is a very constrained one in Ireland.

In terms of training and upskilling, since 2017, Ireland has instituted a programme of training and support for family carers. This is on an ad hoc basis, funded from unused funds in dormant accounts in credit institutions and unclaimed life assurance policies and is directed more at support than training (e.g., supportive apps, information, self-help and self-care or support (through networks and clubs, Facebook apps, for example).[278] Other than this, there are no moves towards skilling or upskilling or indeed skills validation for informal learners to assist them in becoming LTC professionals.

The challenges to ensuring a quantitatively and qualitatively adequate LTC workforce to meet the rising demand for LTC and providing a choice and support for informal carers are huge in Ireland. There are quantitative, volume, challenges but in addition to this the training infrastructure and degree of professional recognition of the value of the sector are low. There is a relatively low level of training in the sector – according to OECD the job of care assistant for older people requires just 36 weeks of training.[279] The sector is also highly informalised (in terms of the degree of dependence on informal care in particular) – the proportion of people reporting providing more than 20 hours of care per week in 2016 was 41 % in Ireland compared to 22.2 % in EU-27.

## 2.4 Financial sustainability

By international standards, Ireland's spending on LTC is low, with recent estimates placing it at 1.3 % of GDP in 2019 compared to 1.7 for the EU-27. The projected expenditure under the reference and risk scenarios are 1.6 % and 1.8 % respectively for 2030 and 2.4 % and 3.2 % respectively for 2050. These rises are very significant, especially those for the longer term (implying a nearly trebling of the 2019 expenditure levels), indicating significant costs involved for Ireland in relation to a shift between informal and formal care and further development of the LTC system. The imbalance in the financial system towards the funding of residential care means significant unmet need as by far the greater usage of services is on the homecare front with just 4 % of the population aged 65 and over in residential care compared to some 10 % using home care services (data for 2015) (Wren et al., 2017).

There are several challenges in relation to financial sustainability. First, the Irish system of LTC tilts in the direction of incentivising residential care, which is arguably an unsustainable and more expensive policy. It has been suggested that Ireland lacks a sustainable funding

[277] Care Alliance Ireland, 2020.
[278] Daly, M., 'Supports for Family Carers in Ireland', *ESPN Flash Report* 2019/04, European Social Policy Network (ESPN), European Commission, Brussels, 2019.
[279] OECD, 2019.

model.[280] For example, the Fair Deal Scheme is designed and budgeted by the state around the premise that some of the public costs will be recoverable from the future sale of the housing asset of the person receiving care. However, with falling levels of home ownership and the falling value of property, the hopes for funding from these sources may well not be realised. Even though the assets contribution has been increased, the yield is a smaller private contribution to LTC than was expected.

Secondly, there is the high and rising cost of such care in Ireland. As well as being a challenge for government this too challenges individuals and their families. Thirdly, there are issues with regard to what is covered by the home care scheme in particular. As mentioned this is free, but it does not cover activities (and costs involved) in laundry and shopping for example. The OECD[281] has calculated that the current level of public support does not bring relative income poverty levels back to pre-LTC levels: while 20 % of the entire older population in Ireland are at risk of income poverty, should they need home care for moderate needs and have access to social protection, that share would go up to 40 %. In other words, there is a higher risk of poverty associated with needing LTC, even after receiving public support. It suggests that one way to fill this gap is to introduce an income-tested cash-for-care scheme for more economically vulnerable older people to pay for the costs of help with laundry and shopping. Residential care is also associated with income and asset deprivation. OECD[282] identifies Ireland as one of the countries where the out-of-pocket costs for older people with mean net wealth are higher than their incomes, implying that care recipients deplete their assets to pay for residential care.

### 2.5 Country-specific challenges regarding LTC for other age groups in need of care

There is some evidence to suggest that those in households containing people with disabilities and other working-age households are significantly less likely than older people in need of help to be receiving professional home care (Grotti et al., 2019).

## 3 REFORM OBJECTIVES AND TRENDS

There have been no major reforms affecting LTC in Ireland between 2017 and 2020. Some more minor reforms include the incremental uprating of the ‘carer’s allowance’ and ‘carer’s benefit’ and easing of the conditions of receipt to allow greater flexibility. In general, over the last decade or so, there has been a thrust to treat ‘carer’s allowance’ in a similar way to some of the other income supports, e.g., ‘jobseeker’s allowance’, in giving people access to some activation services.

Another minor reform has been in terms of training and support for carers which has been in place since 2017. This is on an ad hoc basis, funded from unused funds in dormant accounts in credit institutions and unclaimed life assurance policies and is directed more at support than training (e.g., supportive apps, information, self-help and self-care or support (through

[280] Age Action Ireland, *Priorities for Budget 2020*, Age Action, Dublin, 2019.
[281] Cravo Oliveira Hashiguchi and Llena-Nozal, 2020, p. 101.
[282] Cravo Oliveira Hashiguchi and Llena-Nozal, 2020, p. 55.

networks and clubs, Facebook apps, for example). Other than this, here are no moves towards skilling or upskilling or indeed skills validation to informal carers to assist them in becoming long-term care professionals.

Ireland has not received any Country Specific Recommendation on LTC.

***Planned reforms and on-going legislative process and debates***

***Introduction of a statutory basis to homecare*** *– responding to the major review of health and care services – Sláintecare (Committee on the Future of Healthcare 2017)*[283] *- the (now former) government announced that reform would be undertaken to provide a funding basis for homecare as a well as a statutory scheme which would operate a regulatory model for a uniform homecare service. Preparatory work has been undertaken, including background research on practice elsewhere and a public consultation. An announcement was promised on the details of the new statutory provision in January 2020 but nothing has of yet been announced. Budget 2020 made a commitment to pilot a statutory home care scheme but there are no indications that this has been followed up on.*

***Incremental increases in the funding and volume of home care services***

***Some ad hoc training and support initiatives for informal carers***

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The challenges are huge for Ireland as the current system – especially in regard to home care – is ad hoc, under-funded and faced with significant structural problems. In particular there are workforce-related challenges, which include not just volume but also training and the provision of support. There are serious quality challenges, especially in the home care sector where no statutory overview or quality benchmarks prevail.

Health service reform is high on the political agenda in Ireland – and indeed could conceivably be elevated in importance by the COVID-19 outbreak. A coalition of three parties was formed in June 2020. In this context it is important to note that LTC figured quite strongly in the different parties' election manifestos.

The following would be some worthy reforms:

- ensuring that the reconciliation of care with professional life envisioned by the formal status for informal carers includes greater flexibility in working schedules (e.g. starting and finishing times, establishment of a bank of hours, concentrated working schedule, incentives for tele-working) in order to facilitate the caring needs of jobholders (bearing in mind possible gender impacts);
- ensuring concrete definition of the quality framework for informal care and its enforcement along with the similar framework for formal care;
- revising entitlement to LTC benefits, especially cash benefits, ensuring a closer linkage to the level of dependency rather than focusing excessively on means-testing criteria;
- developing a process of systematic monitoring and evaluation of public policies in the field, including ex-ante assessments.

[283] Committee on the Future of Healthcare, *Sláintecare Report*, Houses of the Oireachtas, Dublin, 2017.

# 5 BACKGROUND STATISTICS

| *5.1. Demographics* | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 4.5 | 4.9 | 5.5 | 6.2 |
| Old-age dependency ratio, 2019 | | 15.6 | 21.6 | 27.0 | 41.9 |
| Population 65+ (in millions), 2019 | Total | 0.5 | 0.7 | 1.0 | 1.5 |
| | Women | 0.3 | 0.4 | 0.5 | 0.8 |
| | Men | 0.2 | 0.3 | 0.5 | 0.7 |
| Share of 65+ in population (%), 2019 | | 10.8 | 14.1 | 17.6 | 24.7 |
| Share of 75+ in population (%), 2019 | | 4.7 | 5.9 | 8.3 | 12.8 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.3* | 20.8 | | |
| | Women | 20.8* | 22.1 | 22.9 | 24.9 |
| | Men | 17.7* | 19.4 | 20.3 | 22.1 |
| Healthy life years at the age of 65, 2018 | Total | 11* | 12.9 | | |
| | Women | 11.1* | 13.8 | | |
| | Men | 10.9* | 12.0 | | |

**data for 2010*

| *5.2. People in need of LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 245.0 | 307.8 | 406.6 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 101.8 | 148.2 | 247.4 |
| | Women | | 60.0 | 85.5 | 145.4 |
| | Men | | 41.8 | 62.7 | 102.0 |
| Share of potential dependants in total population (%), 2019 | | | 5.0 | 5.6 | 6.5 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 14.5 | 15.1 | 16.0 |
| Share of population 65+ in need of LTC** (%), 2019* | | 21.3 | 20.9 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| *5.3. Access to LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 3.0 | 3.3 | 3.9 |
| Share of population 65+ receiving care at home (%), 2019 | | | 8.1 | 8.6 | 9.6 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 76.7 | 78.8 | 84.7 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | - | 48.5 | | |
| | Women | - | 51.8 | | |
| | Men | - | 42.9 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 10.8 | 10.1 | | |
| | Women | 12.1 | 11.8 | | |
| | Men | 9.3 | 8.2 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 11.3 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 22.1 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 616.3 | 639.3 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 4.6 | 4.0 | | |
| | % Women | | 87.3 | | |
| Share of population providing informal care (%), 2016 | Total | | 9.4 | | |
| | Women | | 11.0 | | |
| | Men | | 7.8 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 41.0 | | |
| | Women | | 40.5 | | |
| | Men | | 41.9 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.7 | 1.3 | 1.6 | 2.4 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.7 | 1.3 | 1.8 | 3.2 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 34.9 | 55.4 | 55.4 | 56.9 |
| Public spending on home care as % of total LTC public spending, 2019 | 65.1 | 44.6 | 44.6 | 43.1 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 0.0 | 0.0 | 0.0 | 0.0 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 1.9 | 1.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.4 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.0 | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# GREECE

***Highlights***

- In Greece, long-term care (including prevention and rehabilitation services) continues to be an underdeveloped policy area, given that there are no comprehensive formal long-term care services guaranteeing universal coverage.
- Long-term care is based on a mixed 'quasi-system' of services, comprising formal care (provided by public and private entities) and informal care (provided by family carers and paid carers), where primary responsibility for the financial and practical support of dependants rests squarely on the family.
- Increasing the system's coverage, improving the quality of service provision and governance, along with ensuring the availability of formal carers and providing support for informal family carers are among the main long-term care challenges in Greece. Concerted action is needed to ensure that the challenges are adequately addressed.
- Greece still lacks a comprehensive long-term care policy; there is a need for concrete action to implement a major reform of the long-term care system. This becomes even more imperative, given the pressure imposed by the rapidly ageing population and the negative impacts of the financial crisis/economic recession (e.g. cuts in public spending, deterioration in the health of the population, increasing hardship among households, etc.).

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

It should be stated right at the outset that, although Greece's population has decreased over the period 2009-2019 and is expected to decrease further,[284] Greece has one of the highest population ageing rates in the EU. In particular, Eurostat data reveals that the share of people aged 65+ in Greece has been following an increasing trend, from 18.7 % (or 2.1 million people) in 2008 to 22.0 % (or 2.4 million people) in 2019, remaining one of the highest among EU-27 Member States[285]. This is also the case with the share of people aged 75+ (i.e. from 8.7 % in 2008 it increased to 11.2 % in 2019). The challenge that this demographic development poses to long-term care (LTC) becomes even more pressing when one considers that the proportion of people aged 65+ in the total population in Greece is projected to reach 25.8 % (or 2.7 million people) by 2030 and 33.8 % (or 3.2 million people) by 2050. Similarly,

[284] The total population in Greece was estimated at 10.7 million people in 2019, showing a decrease of 3.6 % compared to the population of 2008 (i.e. 11.1 million), while it is projected to be 10.3 million people by 2030 and 9.5 million people by 2050.
[285] EU-27 refers to the current 27 Member States of the European Union

the share of people aged 75+ in the total population is projected to reach 13.3 % by 2030 and 19.7 % by 2050.[286]

Furthermore, Eurostat data reveals that the old-age dependency ratio (share of people aged 65 or above relative to those aged 15-64) increased from 28 % in 2008 to 34.6 % in 2019, remaining higher in relation to the EU-27 average (i.e. 31.4 % in 2019). Worse still, the old-age dependency ratio for Greece is projected to grow from 34.6 % in 2019 to 41.9 % in 2030 and to 62.6 % in 2050, well above the EU-27 average which is projected to rise to 39.1 % and to 52 % respectively. In addition, Eurostat data reveals that life expectancy at age 65 (i.e. the average number of additional years of life that a survivor to age 65 will live beyond the age of 65) increased slightly over the period 2010-2019, standing at 20.4 years in 2019 – 19.0 years for men and 21.7 years for women.

Demand for LTC is expected to rise even more, given that the healthy life years at 65 indicator, which measures the number of remaining years that a person aged 65 is expected to live without any severe or moderate health problems, shows a decreasing trend for both men and women over the period 2010-2018 in Greece. In particular, in 2018, men aged 65 could expect to live in a healthy condition for 7.4 years (against 8.7 years in 2010), while women aged 65 could expect to live in a healthy condition for 7.2 years (against 8.2 years in 2010).

According to the latest available data concerning people in need of LTC in Greece, the share of population 65+ defined as having at least one severe difficulty in ADLs and/or IADLs was 29.1 % in 2019. In addition, the share of potential dependants in the total population in Greece was 9.7 % (or 1.034 thousand people) in 2019, which is above the EU-27 average (i.e. 7 % in 2019). Projections indicate that the share of potentially dependent people in the total population is estimated to reach 10.6 % (or 1.090 thousand people) by 2030 and 12.6 % (or 1.195 thousand people) by 2050.

Looking at all this, it becomes evident that Greece is facing significant demographic changes which are expected to trigger an ever-increasing demand for LTC services in the country. What is of rising concern, however, is that this challenge - adapting service provision so as to cover the ever-increasing demand - is barely being addressed in Greece, considering that LTC has never been given due attention by either governments or policy-makers, and is a rather neglected policy area.

## 1.2 Governance and financial arrangements

LTC in Greece lacks a comprehensive legislative framework, along with a clear-cut strategy underpinned by an integrated approach, while governance and organisational arrangements are by and large inadequate. Although there is a variety of care structures and programmes concerning the provision of LTC services in the country, these do not operate under a rationalised, well-organised and institutionalised body. The Greek LTC system relies heavily on informal care, where the family plays the dominant role in the provision of LTC, and that is the main determining feature of the LTC system in the country. Although there is no legal

[286] All data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.

obligation for children to care for their parents in Greece, there is a strong cultural expectation for relatives to care for the older members of the family.

As to the division of responsibilities, given that LTC in Greece lacks a comprehensive legislative and governance framework, the system continues to be highly fragmented and unstructured. As a result, the provision of LTC services in the country is based on various legal regulatory frameworks that govern the licensing and operation of the various types of LTC structures.[287] More specifically, the regional authorities are responsible for the licencing (establishment and operation) and monitoring processes of the institutional/residential care services, while local authorities undertake operating the structures which provide community-based LTC services.

Turning to examining public expenditure on LTC (health and social) in Greece, as evidence shows, this was only 0.2 % of GDP in 2019, which is significantly lower than the EU-27 average (i.e. 1.7 % of GDP). Moreover, according to the latest available data of the System of Health Accounts for the year 2018, Greece allocated only 2.1 % of overall health spending to long-term health care services.[288] As to the financing of long-term health care, evidence suggest that 79 % was covered by the social insurance system (compulsory contributory healthcare financing schemes), 18 % by the State (general government schemes) and 4 % by non-profit institutions serving households (non-profit institutions serving households-NPISHs financing schemes), while there is no data recorded as to the financing from household out-of-pocket payments and private insurance payments. It should be noted, however, that this does not reflect the actual situation in Greece; although out-of-pocket payments represent a large share of total health spending, the data on such payments is underestimated, since they do not take account of the extensive use of informal payments for healthcare (including LTC). What is more, there is no data available as to the expenditure for long-term social care for older people, which is heavily based on private payments (informal payments).

## 1.3 Social protection provisions

State support for non-self-sufficient older people and people with disabilities (children and adults) in Greece includes disability benefits, limited direct provision of residential care, coverage of some care needs through public social insurance, and indirect support via tax reductions.

Social insurance coverage entails the provision of old-age and disability pensions by the 'digital National Agency for Social Insurance' (e-EFKA). There are also two cash benefits - of limited coverage - provided directly to people with disabilities (including older people) with care needs, which are funded by the e-EFKA. The first one is the 'total invalidity benefit', which is granted to old-age pensioners who are blind and to invalidity pensioners provided that their condition requires constant supervision and support from a third person (total invalidity). In order to be eligible for this kind of benefit, pensioners must have a

[287] There are some legal regulatory frameworks that apply to different LTC structures and providers. These frameworks set specific requirements and minimum standards (e.g. staff ratios and qualifications). The emphasis is placed on the licensing process, which concerns mainly the fulfilment of these standards by the providers.
[288] ELSTAT, *System of Health Accounts (SHA) of year 2018*, 2018a. https://www.statistics.gr/en/statistics/-/publication/SHE35/-.

medical assessment by the Centre for Certifying Invalidity (KEPA) certifying that their disability is of 80 % or more and that they need assistance from another person. The amount of the total invalidity benefit is equal to 50 % of the pension received and cannot be more than EUR 671.40 per month. The second benefit is the 'non-residential care benefit' which is provided to insured persons and pensioners receiving invalidity, old-age or survivor's pensions, as well as to the members of their families (including children with disabilities) who suffer from specific diseases, on the condition that they do not receive the total invalidity benefit. The monthly amount of the non-residential care benefit is equal to 20 times the daily minimum wage of the unskilled worker for 2011, that is a total amount of EUR 671.40 (20 x EUR 33.57 daily wage).

In addition to disability pensions and benefits, e-EFKA also provides funding for healthcare services for insured people with disabilities and people who need long-term healthcare. These services are provided in public institutions and hospitals through the National Organisation for the Provision of Health Services (EOPYY), while a number of private clinics contracted with EOPYY also provide long-term healthcare (mostly to terminally ill people).

As for the public formal LTC services, these are financed by the Ministry of Health and the Ministry of Labour, Social Insurance and Social Solidarity, as well as by e-EFKA. They entail mainly the provision of institutional/residential care and community-based care services. It should be noted that the admission of older people (aged 65+) to these public residential institutions follows referral by local authorities' social services, the regional social welfare centres or public hospitals. The referral is based on criteria such as economic hardship (though existing legislation does not define a specific income threshold) and severity of need (isolation, exclusion, family crisis, lack of both family support and financial means, etc.). After the initial referral, there is no follow-up visit by the relevant authorities. The care services provided in these institutions is free of charge.

Moreover, there are some other state-financed (non-contributory) disability/welfare benefits (in cash and in kind) that target people who are in need of care because of a specific chronic illness or incapacity.[289] These benefits are provided by the newly established Organisation for Welfare Benefits and Social Solidarity (OPEKA).[290] It should also be noted that there is one targeted housing benefit with extremely low coverage, although no information is available with regards to the number of beneficiaries and the take up rates. In particular, the State provides for a means-tested 'housing allowance' addressed to uninsured and financially weak older people aged 65+. They are required not to own a house and not to have any source of income or any property that can cover their housing needs. The amount of the benefit can be up to EUR 360 per month and it is paid directly to the owner of the rented premises.

[289] Depending on the invalidity/disability level and the kind of chronic illness, recipients are entitled to different levels of care provision. The level of the disability/welfare benefit is positively related to the level of disability. The amount of the disability cash benefit ranges between EUR 165 and EUR 697 depending on the invalidity/disability level and the kind of chronic illness.

[290] OPEKA is the single payment authority for all welfare benefits, including disability benefits, 'Social Solidarity Income' benefit, children's benefits and other welfare benefits.

It should also be highlighted that there are no cash nor in-kind benefits for the carer. Family carers can only benefit indirectly from some income tax relief, which can be claimed by them for supporting a relative with disabilities.

Finally, it is considered necessary to point out that there are no arrangements currently in place as regards the evaluation of care needs. The only exceptions are the Centres for Certifying Disability (KEPA), which are responsible for the evaluation of the level of disability. These centres, which in practice function as health committees, are authorised to assess the level of disability, which is the necessary prerequisite for eligibility to receive the disability/welfare benefits. The disability levels are set at: 50 %, 67 % and 80 %.

## 1.4 Supply of services

LTC in Greece is based on a mixed 'quasi-system' of services comprising formal (provided by public and private entities) and informal care, with primary responsibility for the financial and practical support of dependants resting firmly on the family. Formal LTC services in Greece entail mainly the provision of institutional/residential care and community-based care services, while the provision of home care services is rather limited. It should be noted, however, that the services provided are of limited coverage, and their supply falls well short of demand; thus, informal care (provided by family carers and paid carers) is estimated to cover the lion's share of the need for LTC among the Greek population, though official relevant data is not available.

More specifically, public formal LTC services entail mainly the provision of institutional/residential care and community-based care services. Residential and semi-residential care for adults and children with disabilities and for people living in poverty aged 65+ who live alone and are in need of care is provided by the state through 12 regional 'social welfare centres', which (in 2017)[291] consisted of 44 'social care units':[292] 21 chronic illness nursing homes for adults with disabilities and older people, 13 social protection centres for children, six rehabilitation centres for people with disabilities[293] and four other relevant structures[294] (legal entities of public law).[295] All these care centres are financed by the state budget and by per diem fees paid by EOPYY.

With regards to the 21 chronic illness nursing homes for adults with disabilities and older people, it should be noted that each of them has various sub-units that provide both residential and semi-residential care. Most of these branches/structures focus on adults with disabilities (including the older people with disabilities), but some of them provide care exclusively for deprived older people. Available data (ELSTAT, 2018) shows that, in 2017, these units

[291] These are the latest available data; the survey on social care units is biennial.
[292] Social care units include: units for people with special needs/chronic diseases, units for child protection, units for the recovery and rehabilitation of people with disabilities, centres of physical and medical rehabilitation, miscellaneous (diagnostic and therapeutic centres for pervasive developmental disorders), other legal entities of public law.
[293] The rehabilitation services (outpatient) provided by the centres for recovery and physical and social rehabilitation (KAFKA) and the centres for education, training and social support for people with disabilities (KEKYKAMEA) have been transferred to the National Health System and the public hospitals and are now provided through the centres for physical and medical rehabilitation.
[294] These include: the National Centre for Social Solidarity (EKKA), the National Foundation for the Deaf (EIK) and the Centre for Education and Rehabilitation for the Blind (KEAT).
[295] ELSTAT, *Monitoring the work on Social Care and Protection Units: year 2017 (biennial)*, Press Release, 2018.

employed 1227 people and provided services to 2047 patients (in both residential and home care). It should be noted, however, that the number of available places falls short of demand, and there are long waiting lists.

There are also 510 community residential structures for mentally ill persons. These provide accommodation, care and protection services (sheltered boarding houses and apartments, sheltered workshops, etc.) to about 4100 beneficiaries. They are operated by public and non-profit organisations, and they are financed by the state and EOPYY. In these structures, there are about 2100 beds in sheltered boarding houses (or hostels) for older people with mental health problems that can be counted as LTC beds. In addition, there are 338 beds in public psychiatric hospitals that can be used for the LTC of chronically mentally ill persons.[296]

LTC for incapacitated older people (mostly in poverty or living alone) is also provided by approximately 240 care homes (residential and nursing care facilities) that are run by private (for-profit and non-profit) organisations and local authorities[297] and are mainly located in urban areas. Yet, official reliable data regarding the actual number of these facilities and their capacity is not available. Almost half of the care homes are situated in the Greater Athens Area, and the vast majority are run by private (for-profit) enterprises; the remainder are managed by the Church, charitable organisations and local authorities. The for-profit residential homes are privately paid for by the person in care and their families, while the non-profit care homes are partly subsidised by the State and partly funded by donations (and per diem fees paid by EOPYY for those entitled to social insurance).

Public care facilities and services for dementia and Alzheimer's disease – which affect an increasing number of people in Greece – have, until very recently, been rather negligible; specialised care was mainly provided by a small number of non-governmental organisations (NGOs). To address this gap, efforts have been concentrated on establishing day-care centres for people with dementia, memory and cognitive disorders clinics and palliative care hospices for the terminally ill, which are to be co-funded by the European Social Fund (see also Section 3).

Turning now to other forms of formal LTC, it should be noted that since the beginning of the 2000s, largely thanks to EU-27 co-funding (European Social Fund), there has been a significant increase in LTC services that provide social support and care for older people at home and in the community. These are: a) (semi-residential) day-care centres for people with disabilities, b) (semi-residential) day-care centres for older people (KIFI) and c) services provided to older people and people with disabilities at home ('Help at Home' programme).

As regards the day-care services for older people in the community, these are provided through the 'Day-care centres for older people' (KIFI)[298]. These centres undertake the day care of older people who cannot care for themselves, who have serious economic and health

[296] Data obtained from the Ministry of Health.
[297] Eurofound, *Care homes for Older Europeans: Public, for-profit and non-profit providers*, Publications Office of the European Union, Luxembourg, 2017.
[298] There are also approximately 800 'open protection centres for older people' - (KAPI) operated by municipal enterprises and non-profit entities. However, these have primarily a recreational function (the prevention and medical care services provided are limited).

problems and whose family members cannot look after them because of their work (or for other reasons). In the majority of cases, they are operated by municipalities, municipal enterprises or joint municipal enterprise partnerships and cooperate with local social and health services. Since their establishment, they have been funded mostly by EU-27 resources (European Social Fund) through the Operational Programmes of the 13 regions of the country.[299] According to the latest available data,[300] there were 68 KIFI in operation accommodating about 1500 older people, with a staff of about 300 people.

Another important initiative in this area is the 'Help at Home' programme, which has so far been operated by municipal enterprises and has been mostly funded by EU-27 resources. The programme was launched in 1998 in a limited number of municipalities, but since 2001 it has been rolled out across Greece. Up until 2015 it received financial support from the European Social Fund; since then, the programme has been financed by national resources alone, and its funding has been secured until September 2020 (Law 4635/2019, article 229). At present, there are 859 'Help at Home' schemes in operation, run by 277 agencies (municipalities, municipal enterprises, non-profit organisations, etc.) and providing services to about 70,600 beneficiaries.[301] The schemes provide nursing care, social care services and domestic assistance to older people (aged 78+) and people with disabilities (irrespective of age) who live alone and face severe limitations (mobility problems, etc.) in their everyday lives, and who fulfil specific – rather strict – income criteria.[302] About 3000 people (social workers, nurses, physiotherapists and home helpers) are employed in these schemes, most of them on a fixed term-contract basis.

In conclusion, although there are various public measures and actions concerning the provision of LTC services in Greece, they are inadequate to meet the ever-rising needs in this area, while there is a clear imbalance between formal and informal care provision. The lack of hard evidence concerning the actual capacity and the size and composition of the workforce of all LTC service providers[303] remain among the main drawbacks which continue to prevail in the LTC policy in Greece. All in all, LTC in Greece is in need of urgent reform.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

LTC (including prevention and rehabilitation services) has, for years now, been an underdeveloped policy area, given that there are no comprehensive formal LTC services that guarantee universal coverage. Although relevant official statistical data concerning both demand for and supply of LTC services/facilities is not available, everything points to the fact that formal care is available to only a small number of beneficiaries. This is supported by

[299] It should be noted that EU funding for the operation of these centres has been secured until December 2022.
[300] EETAA, *Local Authorities in Numbers, Special Edition of the Hellenic Agency for Local Development and Local Government (EETAA)*, Athens, 2017.
[301] EETAA, EETAA's Newsletter August-October 2019. https://www.eetaa.gr/newsletter/teyxos10.pdf
[302] It should be noted that the income criteria vary among the 'Help at Home' schemes. In most cases the beneficiary's annual income cannot exceed EUR 7500 - EUR 8000.
[303] See Section 5 'Background Statistics'.

Eurostat data, which shows that in 2017 for every 100,000 inhabitants there were only 39.4 LTC beds in nursing and residential care facilities; this is the second lowest ratio in the EU-27 member states.[304] Moreover, there is an imbalance of service provision due to the geographically uneven development of care services, since the majority of the existing services are located in the urban areas of the country (mainly Athens and Thessaloniki). This implies that access to LTC is heavily dependent on where the person in need lives. This constitutes one of the main barriers of access to LTC, especially for those living on the islands and in isolated rural areas of the country.

As to the home care services provided by professionals or by a community organisation in Greece, latest available data from the European Health Interview Survey (EHIS) reveals that in 2019 only 7.3 % of people aged 65+ used such services for personal needs in the past 12 months. In addition, according to the relevant latest available EU-SILC data (2016), 63.3 % of households in need of LTC services did not use professional homecare services because they could not afford it. Furthermore, 5 % of households in need of LTC services declared that they did not use homecare services because there were no such services available.[305]

There are several other barriers that have been identified concerning access to and availability of LTC services (including home care services). According to the latest available data (European Quality of Life Survey 2011),[306] more than 80 % of LTC service users in Greece experienced difficulties with availability (e.g. waiting lists, lack of services), while over 70 % of service users experienced difficulties with access (e.g. because of distance or opening hours). An example demonstrating this is that the care services provided through the public day-care centres for older people and the 'Help at Home' programme are available only in the morning and early afternoon and for up to eight hours per day.

Furthermore, most of the existing public formal LTC services entail rather strict eligibility criteria; that makes them inaccessible to many people in need of such care. As Tinios argues 'those left out are probably the majority of those who need long-term care; they would be excluded either *de jure* through the exclusion criteria or *de facto* through the limited number of places available'.[307]

Overall, there is an urgent need to increase the system's capacity, so as to meet the demand for affordable LTC services. That constitutes the most profound challenge in this policy area. However, and most importantly, action to increase the system's capacity should go hand in hand with efforts to ensure sufficient quality of LTC services provision.

## 2.2 Quality

When it comes to examining the quality of LTC in Greece, it is considered necessary to point out, right from the beginning, that there is no national or sub-national definition of LTC

[304] The number of LTC beds in nursing and residential facilities in the great majority of EU Member States ranged from 400 to 1100 per 100,000 inhabitants. See Eurostat online database [hlth_rs_bdsns] and Section 5 'Background Statistics'.
[305] See Section 5 'Background Statistics'.
[306] Eurofound, *Third European Quality of Life Survey – Quality of life in Europe: Impacts of the crisis*, Publications Office of the European Union, Luxembourg, 2012.
[307] Tinios, P., 'Greece: Forced transformation in a deep crisis' in Bent Greve (ed.*), Long-term Care for the Elderly in Europe: Development and prospects*, Taylor and Francis, London, 2017, pp. 93-106.

quality in Greece neither in the context of the healthcare sector nor of the social sector. This is congruent to the fact that the system is strongly based on informal LTC and, consequently, formal services play rather a residual role in the provision of LTC in Greece.

Along with the absence of a definition of LTC quality, there is also a lack of a general LTC quality framework that would apply to all types of support (residential or home care) and to all kinds of providers (public or private, for-profit/ not-for-profit); neither is there a general healthcare and social services quality framework that applies to LTC. Needless to say, there are no negative or positive economic incentives linked with the quality performance of the LTC services provided.

However, in the absence of a LTC quality framework in the country, quality assurance is mainly based on a set of pre-determined standards (structure-oriented and employment-related), which are included in the different legal regulatory frameworks that govern the licensing and operation of the various types of LTC structures. In other words, the emphasis is placed on the licensing process, which concerns mainly the fulfilment of certain criteria/standards by the providers, while monitoring and control of the operation of the structures is subject to on-site inspections by the competent services of the regional authorities. [308] These licensing and monitoring processes apply to both the residential structures (i.e. care homes for older people)[309] and the semi-residential structures (i.e. day-care centres for older people-KIFI),[310] though their established standards differ. The responsibility of these processes lies with the competent services of the regional authorities. It should be noted that there is not any regulatory framework that sets specific quality standards for the 'Help at Home' programme.

Moreover, it is worth noting that in spite of the fact that informal care covers the lion's share of the need for LTC in the country, Greece continues to lack a clearly formulated public policy and policies for the regulation of informal (paid) carers and for the support of informal family carers. Needless to say, there are no assessment tools or monitoring arrangements concerning the quality of informal care services.

It therefore becomes evident that, apart from increasing the capacity of the system so as to meet the rapidly growing demand for care, efforts should also be concentrated on improving quality and on setting up appropriate governance arrangements. Nevertheless, addressing effectively the challenge of quality requires, among other things, an adequate number of skilled professional carers, as well as trained and well-informed informal carers.

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[308] As to the monitoring process, in particular, this involves on-site inspections which are carried out by social workers (the so-called 'social advisors'), who are employees of the regional authorities, throughout the period of operation of these structures.

[309] There exists a legal regulatory framework which sets a number of requirements for the licencing (establishment and operation) of private for-profit and non-profit care homes for older people (residential and nursing care facilities). These requirements concern mainly structure-oriented standards, namely minimum building standards, maximum number of places, building safety standards as well as staff composition and staff ratios. For more information see Ministerial Decision Π1γ/οικ.81551, Official Journal of Government, Issue No. 1136, Vol. B', 6 July 2007 (in Greek).

[310] There is a distinct legal regulatory framework which sets the prerequisites for the establishment and operation of the 'day-care centres for older people-KIFI'. These prerequisites take the form of minimum standards mainly with regard to infrastructure and employment (staff ratios and qualifications). For more information see Ministerial Decision Π1γ/ΑΓΠ/οικ.14963, Official Journal of Government, Issue No. 1397, Vol. B', 22 October 2001 (in Greek).

## 2.3 Employment (workforce and informal carers)

As already noted, there is a shortage of public LTC services, which implies that the number of personnel engaged in the provision of formal LTC is likely to be very limited. Yet, there is no aggregated data available as to the formal LTC workforce nor any information as to their specific characteristics (age, gender, education, qualification etc.).

The only available data reveals that in 2017 there were approximately 1227 people working at the 21 chronic illness nursing homes for adults with disabilities and older people (ELSTAT, 2018). Moreover, according to the latest available data (EETAA, 2017), it is estimated that the semi-residential day care centres for older people (KIFI) have a staff of about 300 people. It should be noted, however, that given the fact that the operation of KIFI is secured from EU-27 funding and, in particular, from the European Social Fund, the personnel engaged is on a contract basis, which, in turn, implies that they are confronted with persistent employment insecurity and delays in their payments. This was also the case for the 3000 people working at 'Help at Home' programme until very recently. More specifically, in December 2018, the adoption of Law 4583/2018 secured the permanent nature of the 'Help at Home' programme in the local authorities and subsequently its funding by the state budget. The necessary procedures to hire about 3000 carers under open-end contracts are currently underway.[311]

Nevertheless, according to the latest available data,[312] in 2016, there were less than one (i.e. 0.1) formal LTC worker per 100 people aged 65+ in Greece, compared to 3.8 LTC workers for EU-27. Note should be made of the fact that, in Greece, women represent 95.8 % of the total number of formal LTC workers.[313]

Apart from the fact that LTC in Greece relies heavily on informal care services, it appears that the job of professional carer (formal carer or formal carer of older people) has not yet been accorded any recognition. As a result, carers face significant difficulties in finding appropriate jobs; on top of everything else, there are hardly any opportunities for their professional development, training or lifelong learning. The lack of recognition is related to the fact that LTC provision in Greece is not underpinned by a clearly defined comprehensive policy, and it hardly complies with certain minimum quality requirements. That is, it lacks any specific regulation and legislation that would ensure that appropriate standards of provision, quality assurance arrangements, staff ratios, staff training, etc. are put in place. This, in turn, implies that there are neither specific working conditions nor specific types of employment contracts for those employed in the formal care sector. Employment contracts in the sector vary, depending mainly on the specialisation of the carer (social worker, nursing staff, etc.) and on whether the carer is employed by a public or a private agency.

As for informal carers, it should be noted once more that informal care in Greece is mainly provided by family and relatives, as well as by unskilled female migrant carers, mostly with

[311] European Commission, 'Joint Report on Health Care and Long-Term Care Systems and Fiscal Sustainability, Country Documents 2019 Update', *Institutional Paper* 105, European Commission, Brussels, 2019.
[312] OECD, *Health at a Glance 2019: OECD Indicators*, OECD Publishing, Paris, 2019. https://doi.org/10.1787/4dd50c09-en.
[313] See Section 5 'Background Statistics'.

informal employment arrangements (undeclared work), [314] though relevant data is not available.[315] However, Greece continues to lack a clearly formulated policy and policies for the regulation of informal (paid) carers and for the support of informal family carers. By and large, family carers in Greece are viewed by the state primarily as a resource and are hardly considered to have their own need of support.

The only support services available to carers are those provided by a small number of NGOs, operating mainly in Athens and other big cities and offering – among other things – information, practical advice, psychological support and group training. Most of these services target family carers of people suffering from specific diseases, such as dementia or Alzheimer's disease and – to a lesser extent – blindness and cancer. It is rather evident that the capacity of such services can hardly meet carers' needs all over Greece (although no actual data is available to support this).

## 2.4 Financial sustainability

In order to extend and upgrade public formal LTC services in Greece, sufficient financial resources are needed; but this challenge is barely being addressed. Expenditure for LTC in Greece remains at a very low level; according to the latest available data public expenditure on LTC as a percentage of GDP was 0.2 % in 2019, which is far below the EU-27 average of 1.7 %.

Moreover, according to European Commission projections (reference scenario), public spending on LTC as a percentage of GDP in Greece will stagnate at 0.2 % of GDP until 2050. Public spending will thus remain well below the EU-27 average (1.7 % in 2019 and 2.5 % in 2050). When taking into account the impact of non-demographic drivers on future spending growth (risk scenario), LTC expenditure is expected to increase by 0.4 percentage points (p.p.) of GDP, from 0.2 % in 2019 to 0.6 % in 2050.

Taking all this into account, it becomes evident that questions are being raised as to whether the financial sustainability of public expenditure on LTC in Greece can be ensured, so as to cover the ever-increasing needs in this area, especially under the high pressure imposed by population ageing (see Section 1.1.). Population ageing is expected to trigger an ever-increasing demand for LTC services; this, in turn, will increase pressure for higher public spending in this policy area in the medium- and long-term.

[314] The vast majority of the female migrant carers are hired (and paid) by the dependant's family – or in some cases by the dependent person – on the basis of an oral agreement, rather than a formal employment contract. The carers often live with the dependent person, providing care on a 24-hour basis, while the responsibility for monitoring care resides – by and large – with the women of the family. See Ziomas, D., Konstantinidou, D., Vezyrgianni, K. and Capella, A., *ESPN Thematic Report on Challenges in long-term care – Greece*, European Social Policy Network (ESPN), European Commission, Brussels, 2018.
[315] The only relevant data in this respect is the data from the *2016 EU-SILC ad-hoc module on access to services*. According to this data, the share of respondents in Greece who provide care or assistance to one or more persons needing help due to long-term illness or because of old age was 1.4 %, which is far below the respective EU-27 average of 6.3 % (in 2016). See Section 5 'Background Statistics'.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Promoting independent living for children with disabilities in Greece is among the main LTC challenges linked to age groups other than older people. For many years, residential and residential care for children in Greece remains a rather neglected policy area. It is an area which has never been taken on board the policy agenda of consecutive governments and policy makers alike. As a result, state residential care in an asylum-like environment for children without parental care and children with disabilities, along with the care provided in family-like residential care facilities, remain the predominant alternative care service available in Greece.[316]

No significant efforts have been made thus far to change this situation, while Greece continues to lack a de-institutionalisation strategy for the children living in these institutions.[317] It should be noted, however, that, in December 2017, EUR 15 million from the national budget were allocated by the Greek government for the implementation of a pilot programme for the de-institutionalisation of people with disabilities and, in particular, of children with disabilities living in degrading conditions in certain residential care structures. The plan is to create and run a number of 'Supported Living Houses' to accommodate the children from these residential care structures and improve their living conditions and the quality of care provided. Yet, the actual activities of the plan to be implemented is not so clear and have not been precisely defined, while there are also concerns about the quality and the sustainability of such fragmented plans of action.

# 3 REFORM OBJECTIVES AND TRENDS

As has been repeatedly emphasised in this report, LTC in Greece has never been given due attention by either governments or policy-makers, and is a rather neglected policy area. This implies that no major reforms have been undertaken over the last few years in this policy area, while there are no ongoing or announced reforms.

However, it should be noted that a few initiatives have been taken in the LTC sector over recent years. These concern the establishment in 2014 of the National Observatory for Alzheimer's and Dementia and the adoption in 2016 of the National Action Plan, which includes the creation of special care units (day-care centres, etc.) and the provision of support for carers.[318] In this context, in September 2017, the government announced the establishment of seven day-care centres, six memory and cognitive disorders clinics and five palliative care

[316] It should be noted that there are definite indications that a number of these institutions continue to operate inefficiently, while in some of them the living conditions there were found to be degrading, especially for children with disabilities. The Greek Ombudsman has urged the competent authorities to undertake the necessary steps and to proceed with taking adequate administrative measures for the alleviation of the abovementioned practices. See: The Greek Ombudsman https://www.synigoros.gr/?i=childrens-rights.el.files.46883 (in Greek).

[317] For a few years now, Greece has been identified by the European Commission among the countries with a specific need for de-institutionalisation reforms. To this end, a budget has been allocated by the European Structural and Investments Funds and in particular by the European Social Fund (ESF). Yet, Greece continues to lack a de-institutionalisation strategy in this respect, and thus, the funds earmarked for this purpose have not as yet been absorbed.

[318] Minister of Health (2016), National Action Plan for Dementia–Alzheimer's Disease. http://www.alzheimer-drasi.gr/images/doc/ethniko_sxedio_drasis.pdf (in Greek).

hospices for the terminally ill, which are to be co-funded by the European Social Fund.[319] The plan also aims to facilitate the linkage of these services with all the other social care services and programmes targeting the older population. Although there is no official data available either on the progress of their actual operation to date or on the extent of their coverage, it appears that eight new day-care centres for people with dementia have been established in large cities of the country; five memory and cognitive disorders clinics are in operation within general hospitals, while two palliative care hospices for the terminally ill are expected to be in operation soon.

Another positive development is the establishment in mid-2018 of an institutional setting for the provision of 'Integrated Care for Older People'. In particular, 150 'Integrated Care Centres for Older People' were established, which operate as branches of the 'Community Centres' in various municipalities of the country.[320] They provide information and support services exclusively to older people in order to increase the accessibility of LTC services available. In addition, they take care of the coordinated operation of the existing care services for older people, namely open protection centres for older people (KAPI), day-care centres for older people (KIFI) and the 'Help at Home' programme.

Moreover, note should be made of the fact that the reform of the assessment system of disability, which is currently underway in Greece, is expected to strengthen the provision of in-kind benefits and services for people with disabilities and, thus, is linked with LTC. In particular, Greek authorities, under the post-programme surveillance framework,[321] have committed to 'apply to all disability benefits the new approach for disability determination based on both medical and functional assessment by mid-2019'. In this context, a pilot project has been underway, to explore new administrative procedures and appropriate criteria, based on the functional ability, along with medical criteria, for disability assessment. The findings of this pilot project are expected to lead to the design of a new disability assessment system to be applied to all contributory disability and (non-contributory) welfare benefits. Yet, this pilot project has not been finalised as of yet and the authorities have agreed to provide a new revised timeline for its national rollout by April 2020.[322]

Finally, in response to the COVID-19 outbreak, the authorities undertook, among other things, a number of social distancing measures to contain the spread of COVID-19 among older people. In this context, the operation of all institutions providing LTC services was

[319] Greek Association of Alzheimer's Disease and Related Disorders, *A note for Alzheimer's Disease*, *Quarterly Edition*, Vol. 71, 2017.
[320] The 'community centres' (CC) are a kind of one-stop-shop, which are responsible for reception, information and service provision, and for the liaison of citizens -and especially vulnerable social groups- with all social programmes and services available at local level. Currently, there are 241 CC in operation all over the country. All these CCs are run by the municipalities and are funded under the Regional Operational Programmes of the National Strategic Reference Framework 2014-2020 for Greece.
[321] On 21 August 2018, the third economic adjustment programme for Greece (ESM stability support programme) was concluded and the country has entered a post-programme surveillance framework. This is a monitoring framework to ensure that all structural reforms agreed under the economic adjustment programmes will be fully and properly implemented. In this respect, Greece is committed, among others, to continue with efforts to modernise its social welfare system, including pensions and the healthcare sector, as well as to complete the reform of the welfare benefits which constitute the basic elements of a social safety net.
[322] European Commission, 'Enhanced Surveillance Report, Economic and Financial Affairs – Greece', *Institutional Paper* 123, 2020, Publications Office of the European Union, Luxembourg.

safeguarded by undertaking all the necessary measures (suspension of visits, use of protective equipment by staff, quarantine in light of a possible COVID-19 case, etc.) with the exception of the 'open protection centres for older people' (KAPI), the operation of which was suspended. Efforts have also been concentrated on strengthening the municipal social services with the aim to support all people in need (including older people).

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The preceding analysis shows that Greece still lacks a comprehensive LTC policy; there is, therefore, a need for concrete action to draw up and implement such a policy. This need becomes even more imperative in the context of population ageing and the negative impacts of the financial crisis/economic recession (e.g. cuts in public spending, deterioration in population health status, increasing hardship among households, etc.).

To this end, a major reform of the LTC system should be undertaken, along with drastic changes aimed at promoting the reconciliation of caring responsibilities with working life. Among the main ingredients of such a system should be the creation of a regulatory framework and quality standards for the provision of LTC, the establishment of coordination mechanisms that will link the different LTC structures, and the setting-up of a well-organised monitoring and evaluation system. This reform should entail, among other things, the establishment of new upgraded LTC units so as to extend availability and improve access to service provision all over the country.

What is also needed is a legal recognition of the profession of carer, especially of those who look after older people; that will provide more opportunities for the professional development of carers, their training and lifelong learning. As regards to increasing the ability family carers to work, what is needed is targeted active employment measures, along with specific working conditions – on the one hand, to facilitate carers' entry into employment and on the other hand, to make it easier to combine work and care responsibilities.[323] Finally, carer support centres should be established to provide support for family carers at any time, and to help them deal with the specific needs of the people they care for (Ziomas et al., 2018).

[323] Ziomas, D., Sakellis, I., Spyropoulou, N. and Bouzas, N., *ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives – Greece*, European Social Policy Network (ESPN), European Commission, Brussels, 2016.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 11 .1 | 10.7 | 10.3 | 9.5 |
| Old-age dependency ratio, 2019 | | 28 | 34.6 | 41.9 | 62.6 |
| Population 65+ (in millions), 2019 | Total | 2.1 | 2.4 | 2.7 | 3.2 |
| | Women | 1.2 | 1.3 | 1.5 | 1.8 |
| | Men | 0.9 | 1.0 | 1.2 | 1.4 |
| Share of 65+ in population (%), 2019 | | 18.7 | 22.0 | 25.8 | 33.8 |
| Share of 75+ in population (%), 2019 | | 8.7 | 11.2 | 13.3 | 19.7 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.7* | 20.4 | | |
| | Women | 21.0* | 21.7 | 22.9 | 24.9 |
| | Men | 18.2* | 19.0 | 20 | 22.1 |
| Healthy life years at the age of 65, 2018 | Total | 8.5* | 7.3 | | |
| | Women | 8.2* | 7.2 | | |
| | Men | 8.7* | 7.4 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 1,033.7 | 1,089.9 | 1,195.0 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 680.4 | 759.0 | 951.3 |
| | Women | | 408.7 | 457.2 | 572.2 |
| | Men | | 271.7 | 301.7 | 379.1 |
| Share of potential dependants in total population (%), 2019 | | | 9.7 | 10.6 | 12.6 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 28.7 | 28.3 | 29.7 |
| Share of population 65+ in need of LTC** (%), 2019* | | 34.7 | 29.1 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 0.0 | 0.0 | 0.1 |
| Share of population 65+ receiving care at home (%), 2019 | | | 9.6 | 9.6 | 10.8 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 33.6 | 34.1 | 36.5 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 48.5 | 43.1 | | |
| | Women | 50.6 | 45.0 | | |
| | Men | 44 | 38.6 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 8.3 | 7.3 | | |
| | Women | 9.3 | 8.8 | | |
| | Men | 7.1 | 5.3 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 63.3 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 5 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 38.6 | 39.4 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 0.4 | 0.1 | | |
| | % Women | | 95.8 | | |
| Share of population providing informal care (%), 2016 | Total | | 6.7 | | |
| | Women | | 8.0 | | |
| | Men | | 5.5 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 45.9 | | |
| | Women | | 50.5 | | |
| | Men | | 38.7 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.5 | 0.2 | 0.2 | 0.2 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.5 | 0.2 | 0.2 | 0.6 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 2.2 | 83.1 | 80.3 | 74.1 |
| Public spending on home care as % of total LTC public spending, 2019 | 6.3 | 16.9 | 19.7 | 25.9 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 91.5 | 0.0 | 0.0 | 0.0 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.1 | 0.2 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.0 | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | - | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# SPAIN

***Highlights***

- The population aged 65 and over represents 19.4 % of the Spanish population (2019), a percentage that is expected to reach 23.8 % in 2030.
- In 2019, the 'system for autonomy and care for dependency' (SAAD) covered 1,115,183 people aged 65 and over – 80.5 % of the recognised beneficiary population – with benefits and services. Public spending on long-term care (LTC) was 0.7 % of GDP in 2019.
- There is still limited development of homecare and community-based services, and there are territorial imbalances in the supply of services and the different co-payment criteria.
- Formal employment is characterised by excessively high rates of temporary and part-time employment, while informal care work continues to dominate the social structure of care. In 2016, 11.5 % of the population aged 16 or above were carers in Spain, the vast majority of whom were women. Only some of these receive economic benefits to support informal care.
- The Spanish LTC system faces the challenge of improving its effectiveness in the light of the growth of the dependent population, as well as changes in the structure of informal care. This will require: reducing high waiting lists for access to services; expanding the supply of home and community services (the maximum number of hours per month of homecare received by highly dependent people is less than two hours per day); making community care benefits more flexible and compatible; further developing the SAAD in rural areas; standardising the criteria for co-payments in the autonomous communities; strengthening the reconciliation between informal care and working life; and improving co-ordination between the central and regional administrations.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM

### 1.1 Demographic trends

People aged over 65 in Spain currently (2019 data) represent 19.4 % of the population (EU-27: 20.3 %), and the ageing projections for 2030 and 2050 indicate that this figure will reach 23.8 % and 32.7 % respectively (EU-27: 24.2 % and 29.5 %).[324] People aged 75 and over represented 9.6 % of the population in 2019 (EU-27: 9.7 %), and are projected to reach 11.6 % by 2030 and 18.9 % by 2050 (EU-27: 12 % and 17.1 %).

[324] All data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.

The old-age-dependency ratio[325] is projected to increase from 29.5 % in 2019 to 37.2 % in 2030 and 59.5 % in 2050 (EU-27: 31.4 %, 39.1 %, and 52 %).[326] According to these projections, in 2019 and 2030 these figures are slightly lower than the EU-27 average; however, in 2050 Spain will be one of the Member States with the highest percentages of people aged over 65 and over 75, and the highest old-age-dependency ratios. This, together with the fact that Spain is also one of the EU-27 Member States with the highest life expectancy (22.0 years in 2019) and healthy life years (11.4 years in 2018) at age 65, may imply a higher probability that the number of people in need of LTC will increase in the future. The potentially dependent population[327] will increase from 2.01 million in 2019 to 2.32 million in 2030 and 2.92 million in 2050.[328]

In Spain, there are important differences between regions in the percentages of people aged over 65 and over 75, and in the old-age-dependency ratio: in some regions (Asturias, Castilla León, and Galicia), the respective figures are around 25 %, 13 % (both in 2019), and 40 % (in 2018), while in others (Balearic Islands and Murcia) they are around 15 %, 7 %, and 23 %.[329]

## 1.2 Governance and financial arrangements

The current Spanish LTC system emerged in 2007, after the approval in 2006 of Law 39/2006 on the promotion of personal autonomy and care for dependent people (LAPAD). It is currently integrated into the regional social services system.

The approval of LAPAD resulted from a wide degree of consensus among stakeholders.[330] The law established the SAAD. This system defines a universal right for all those who, regardless of age, can demonstrate stable residence in the country for at least five years and one of the degrees of dependency established in the law – moderate (degree I), severe (degree II) or high (degree III).

The central government regulates the basic conditions that guarantee the equal exercise of this right across the country and is also responsible for the information system of the SAAD (SISAAD). By means of the Inter-territorial Council of the SAAD (CISAAD), central government and the regions agree on a framework for intergovernmental co-operation, the intensity of services, the terms and amounts of economic benefits, the criteria for co-payments by beneficiaries, and the scale for the recognition of dependency. The regions represent the

[325] The old-age-dependency ratio is defined as the ratio between the number of people aged 65 and over and the number of working-age people (15-64).
[326] The Spanish National Institute of Statistics estimates that in 2050 31.6 % of the population will be aged over 65, of whom 37.5 % will be 80 and over, reaching nearly 50 % in 2068. The old-age-dependency ratio would rise from 29.2 % in 2018 to an estimated 57.2 % in 2050. https://bit.ly/3dOAN6E.
[327] The population of potentially dependent people is based on an average of the last four years of EU-SILC data on severe 'self-perceived longstanding limitation in activities because of health problems for at least the last six months' (*The 2018 Ageing Report: Economic and budgetary projections for the 28 EU Member States (2016-2070),* European Commission, Brussels, 2018. Available at https://bit.ly/2KAqG8r).
[328] Other projections indicate an increase from 1.4 million in 2016 to 2.2 million in 2030. The proportion of potential dependants (people aged 80 and over) in relation to potential care-givers (aged 45-64) will increase from 22 % to 25 % in 2020 – and to 63 % by the middle of the century, triple the current proportion (Abellán, A., Pérez, J., Ayala, A., Pujol, R. and Sundström, G., 'Dependencia y cuidados', in Blanco, A., Chueca, A. and López-Ruiz, J.A., *INFORME España 2017*, Universidad Pontificia Comillas, Madrid, 2017, pp. 169-234.)
[329] Source: Spanish National Institute of Statistics.
[330] http://bit.ly/2kLPdhn

operational structure of the system, as they have responsibility for managing the register of providers, for inspecting and evaluating degrees of dependency according to the official evaluation scale, and for recognising the right to benefits. The autonomous communities regulate and finance the role of local authorities in the provision of community services (for example homecare or day centers).

In practice, local entities have a very relevant role as they they are the providers of community services, according to each of the regional laws. However, the weight they have in the provision of services is not sufficiently reflected in decision-making within CISAAD.

Spain belongs to the group of EU-27 Member States with LTC systems characterised by medium coverage, mainly financed by general revenue, with informal care still playing a significant role. Informal care work continues to dominate the social structure of care. The financing comes from the National and Regional general budgets and co-payments by the beneficiaries, according to their income and assets, and according to the type of service received. It is financed jointly by central government and the regions. Each regional government may establish a wider set of benefits for its residents.

As we point out in Section 2.4, total estimated public expenditure on LTC has increased progressively since the approval of the SAAD. Although the financial contribution to the SAAD should be similar as between central government and the regions, the contribution by the regions is much higher. There are also differences between the regions with regard to co-payments and the contribution of the regions to the SAAD.

## 1.3 Social protection provisions

Eligibility is determined through an assessment of the degree of dependency; this is carried out by a qualified professional belonging to regional social services, who conducts interviews and direct observation of people in their everyday environment. People's incomes and assets are taken into account to determine the amount and frequency of the benefit.

The degrees of dependency are determined according to the frequency and intensity of the assistance required. Moderate dependency means needing intermittent support at least once per day (degree I); severe dependency means needing extensive support two or three times per day (degree II); and high dependency means needing indispensable and continuous support several times per day (degree III). Once an individual has been assessed as being in need of care, an individualised care plan (ICP) is prepared by the social services, including a list of appropriate services or cash benefits according to the degree of dependency. There is monitoring of dependent people: in cases where dependency is worsening due to a greater frequency and intensity of the assistance required, another assessment is usually carried out in case a new ICP needs to be drawn up.

The SAAD includes different services and cash benefits. Services are detailed in Section 1.4. The cash benefits include cash benefits for informal care at home, personal assistance, and the purchase of services. These cash benefits and their amounts are granted according to people's degree of dependency and economic resources. In the SAAD there are no specific benefits related to people aged over 65. Beneficiaries do not have discretionary use of cash benefits. In the case of the cash benefit for informal care at home, the care must be provided by family

members; only in exceptional circumstances can it be provided by others in the home setting. Households can choose informal carers freely, so long as they meet the requirements. This benefit is granted if the beneficiary has been cared for by non-professional carers in the year prior to the application, and only if there is no suitable formal care available. The amount received may be reduced to reflect compulsory co-payments (depending on the beneficiary's income). Informal carers can subscribe to voluntary insurance through the social security system (between 2012 and April 2019, they were paid for by the informal carers). The resulting allowance must be used to compensate informal carers for their work and the costs of care in a household setting. In practice, these amounts cover only a very small part of the costs of care. However, the public administrations do not usually check whether the money received by the beneficiaries goes towards these expenses. The cash benefit for personal assistance is geared towards hiring a personal assistant for a number of hours, to improve dependent people's personal autonomy and access to work/education, as well as to provide help with daily activities, regardless of the degree of dependency (until 2012, this was only allowed for degree III dependency). The beneficiary may hire an accredited company or a worker registered with the social security system as self-employed. The cash benefit linked to the purchase of services enables the care recipient to contract services from private licensed providers if the public sector is not able to provide these. There is a free choice of professional providers. Services may be home assistance services, daycentres, night centres or residences, depending on what is established in the ICP as to the degree of dependency. The amount received can only be used to contract services. The beneficiaries of cash benefits for personal assistance and the purchase of services are asked to present invoices to account for how the sums they receive are spent.[331]

There are some incompatibilities between cash benefits and services. The cumulation of cash benefits with benefits in kind is not possible, except for services to prevent situations of dependency, to promote personal autonomy, and for tele-assistance.

## 1.4 Supply of services

The main LTC services are the following: technical assistance, homecare, day/night centres, and residential care. There is no free choice of professional providers. Technical assistance includes home tele-assistance (advice via the internet, alert system, monitoring system, etc.), which is offered to people with a moderate degree of dependency who live at home. The homecare service (HCS) can be considered a support service for carers of people with a high degree of dependency. It includes help with personal care. The daycentres have a double objective: 'improving and maintaining the highest possible level of personal autonomy and *supporting the families or carers*' (Article 24 of LAPAD). Night centres provide a respite service and are much less widespread than daycentres; they are considered primarily as a support service for carers. Residential care may be permanent if it becomes the dependant's habitual residence (only valid for degree II or III dependency), or temporary (involving short

[331] Rodríguez Cabrero, G., Marbán, V., Montserrat Codorniu, J., Arriba, A. and Moreno-Fuentes, F.J., *ESPN Thematic Report on Challenges in long-term care: Spain 2018*, European Social Policy Network (ESPN), European Commission, Brussels, 2018. http://bit.ly/2lSbMB9.

stays for convalescence, holidays and illness, or to provide some rest for non-professional carers).

Services are provided through a public network of regional and municipal centres or duly accredited private centres (the latter managed by for-profit, and/or non-profit, organisations) subsidised by the public sector.

Although progressively decreasing, the cash benefit for informal care at home is the most common of all benefits in the SAAD: according to SAAD data, in December 2019, 426,938 beneficiaries received it (30.26 % of all dependent people receiving benefits, compared with 54 % in January 2014); 10.7 % of beneficiaries received a cash benefit linked to the purchase of services; and 0.56 % a cash benefit for personal assistance.[332] In-kind benefits represented over 58 % of all benefits. HCS predominated over residential services. According to the SAAD, 35.22 % of beneficiaries[333] received HCS (tele-assistance, homecare), compared with 12.1 % of beneficiaries receiving residential care (19 % if day/night centres are included), and 4.3 % received prevention benefits.

The care model in Spain is still above all family-based, woman-dominated, informal, and time-intensive. In relation to the workforce (informal and formal care), as we point out in Section 2.3, it is estimated that the working population in the social LTC system is around 275,000 people (in 2019). LTC employment is precarious, with high rates of short-term and part-time employment, and low levels of remuneration. Most informal care-givers aged over 65 are women, and foreign workers represent 12.7 % of those who informally care for dependent people in the home.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

In assessing the LTC system, two population sets among those aged 65 and over must be taken into account. On the one hand, there is the population receiving formal and/or informal social care and healthcare as part of LTC, information on which is collected through Eurostat and OECD[334] statistics. On the other hand, there is the population receiving only social care through the SAAD, a somewhat smaller set, which does not include healthcare services. In the second case, the information provided by the SISAAD on the population aged 65 and over is very general. Information on the distribution of this group by degree of dependency, age, and sex, or the types of services and benefits they receive is available, although it is not published. In this section we assess the public social care system, or SAAD; but at the same time we relate it to the entire formal and informal LTC system.

[332] For more information on SAAD statistics, see Annex 2 National Statistics.
[333] The SAAD does not provide information on the beneficiaries of these benefits disaggregated by age.
[334] Organization for Economic Co-operation and Development.

**Access**

The number of Spanish people considered to be potentially dependent in 2019 was 2,006,800.[335]

According to the SAAD, there were 1,115,183 actual beneficiaries of benefits in December 2019, which was 80.5 % of the total number potentially entitled to benefits (1,385,037), with the remaining 19.5 % (269,854) on waiting lists.[336] Of those receiving benefits, 73 % (809,360) were aged 65 and over, and 54.2 % were over 80. Women over 65 accounted for 53 % of all beneficiaries of the system, and 73 % of all those aged 65 and over.

The most important access problem is the waiting time between applying to the SAAD and receiving confirmation of eligibility to access a service or economic benefit. In 2019, the average waiting time was 426 days, or one year and two months, far exceeding the legal maximum of 180 days. In four regions out of a total of 17, the waiting period exceeded 18 months. These waiting periods mainly affect people over 65, who account for 75 % of all applicants, according to the AEDGSS.[337]

The second problem is the waiting time between the administrative decision recognising the right to a service and the actual granting of access to it, which depends on the availability of a service. Here, there are chronic delays in the SAAD. Although the waiting list was reduced between 2015 and 2019, in the latter year (as noted above) it still affected 269,854 people, including 202,390 people aged 65 and over. In 2019 an estimated 31,000 people died before they could access the service to which they were entitled,[338] the vast majority of them over 65. Waiting times are clearly excessive and contribute to discouraging demand.

There are significant differences in waiting lists and SAAD coverage among the regions: according to information from the SAAD as at December 2019, the waiting lists were as high as 25-30 % in the Canary Islands, La Rioja, Catalonia, and Andalusia. The last two regions alone accounted for 57 % of the people awaiting a benefit in Spain as a whole. By contrast, there are territories, such as Castile and Leon (1.5 %), Ceuta and Melilla (5 %), and Navarra (6 %), where waiting lists are practically non-existent.

In terms of coverage, however, the percentage of beneficiaries in relation to the population was much higher than the national average (2.37 %) in regions such as Castile-Leon (4.4 %), Castile-La Mancha, the Basque Country, Cantabria (all 3 %), and Extremadura (2.6 %); whereas in other regions such as the Canary Islands (1 %), the Valencian Community, and the Balearic Islands (1.8 %) there is clearly room for improvement. If we refer to the population potentially dependent in the future (people aged over 65, and people with disabilities aged under 65), the coverage of the SAAD at the national level would be 10.50 %, with a wide variation by region, from 5.71 % in the Canary Islands to 15.19 % in Castile and Leon (AEDGSS, 2020).

[335] Table 5.2 in Section 5 'Background statistics'.
[336] People entitled to benefits in the SAAD are those who have been assessed as being in need of care in the ICP.
[337] Association of Directors and Managers in Social services (*Asociación de Directores y Gerentes en Servicios sociales* – AEDGSS). See: Observatorio de la Dependencia, *XX Dictamen sobre Dependencia*, Madrid, AEDGSS, 2020. https://bit.ly/2KB6SBD.
[338] Observatorio de la Dependencia, *XIX Dictamen sobre Dependencia*, Madrid, AEDGSS, 2019.

In summary, the coverage of the population aged 65 and over by the LTC system or the SAAD is high but incomplete, and subject to long waiting times for effective access. In practice, this coverage is supplemented, especially for the moderately dependent population, by the system of homecare and tele-assistance provided by the municipalities, in addition to informal care by family members or contracted people.

**Affordability**

**Unbalanced availability of services.** Given that the supply of services and economic benefits is the exclusive competence of the regional authorities, there is a wide diversity of situations, which has to do with the structure of the regional system of social services into which the SAAD is integrated, and with the different levels of political and financial commitment to the system.

During the period 2008-2019, the home-help service network was expanded and is now received by almost 18 % of all SAAD beneficiaries. The existence of two HCS networks in some regions – for people with and without dependency – has created some confusion in demand. During the years when the economic and financial crisis had the greatest impact, some people using the SAAD's HCS, especially those with moderate dependency, switched to the municipal HCS, where the requirements for access are less stringent and co-payment is almost non-existent. This means that the total population receiving HCS is higher than that shown in SAAD figures. HCS, for both dependent and non-dependent people, was actually received in-kind by 672,000 people (7.73 % of the population aged 65 and over) and in cash benefits by 372,000 people (4.3 %) in 2016. The difficulty of achieving effective access to professional HCS is explained more by financial reasons (according to 54.1 % of the population aged 65 and over) than by the lack of availability of the service (7.3 %).

On the other hand, the SAAD family care cash benefit is received by 30.26 % of all beneficiaries, with demand accounted by the deficit in formal homecare and residential services. The imbalance between supply and demand is also evident from the fact that the cash benefit linked to a service (normally intended for residential care) is chosen by almost 11 % of the SAAD beneficiary population, because they cannot find a place either in the public or in the contracted-out, privately managed social services network.

Overall, the SAAD is an LTC system that supports and complements the traditional family care system, which remains the backbone of care for dependent people. This is reflected in facts such as the following: (a) the average benefit for family care is EUR 247 per month after the co-payment (EUR 340 in the case of degree 3 dependency), a benefit enjoyed by 32 % of all beneficiaries and representing 17.7 % of the total cost of the SAAD;[339] (b) in the HCS, the maximum number of hours of care received per month for degree 3 dependency is 54 hours (i.e. less than two hours per day), and for degree 2 it totals 35 hours per month; and (c) the cash benefit linked to a service (almost always residential), received by almost 11 % of all beneficiaries, is EUR 550 per month after deducting the co-payment. If we take into account that the minimum price of a public residence is EUR 2200 per month, the result is that the

[339] Estimating an average hourly cost of EUR 20, in the case of degree 3 dependency, 58 hours of homecare would cost EUR 1080 per month. The benefit in this case represents 31.5 % of this cost.

beneficiary has to assume a second co-payment for the difference between the cash benefit received and the cost of the residence. In contrast, the beneficiary population receiving the residence benefit directly accounts for 12 % of the total, and its cost accounts for 47 % of the total cost of the SAAD (SISAAD, 2019).

The low protective intensity of the SAAD highlights the underfunding of the Spanish system, although there are significant differences between the regions. Dependent people supplement the cost of the LTC system out of their own income and by using informal care. In a sense, the system is an implicit alliance between the public sector and households with dependants.[340]

**Out-of-pocket spending**. As we mention in Section 2.4, co-payments to the SAAD accounted for 20.7 % of the total cost of the SAAD in 2019. Co-payments varied by more than 10 p.p. with respect to the average, between a minimum of 11 % in the Community of Valencia and 22 % in Madrid.[341] The co-payment is calculated on the basis of income and assets and different household circumstances. The current model of co-payment, as a whole, generates quite a few inequalities, although the co-payment calculations usually vary among the regions. As two papers[342/343] argue, the model (especially from mid-2012 onwards) is designed for revenue-raising purposes and is significantly regressive.[344] People in the lower-middle income bracket pay proportionally more than those in the upper-middle income bracket (from three times the IPREM[345]) – for the latter, the inclusion of assets in economic capacity has no effect on the amount of the co-payment, whereas for those with lower-middle income brackets the impact is significant. As a result, as an article[346] points out, the co-payment model for the care of dependent adults needs to be reviewed, and the transparency of information on user payments needs to be improved.

## 2.2 Quality

To ensure quality, the Spanish LTC system has three instruments: (a) a national and regional regulatory system; (b) formal ex ante quality controls; and (c) good practices.

(a) The LAPAD provides the main regulatory framework for LTC in Spain. This law does not include a specific definition of quality in LTC, although Articles 34-36 refer to quality in terms of services and the training of professionals and carers. The regulation of these aspects is developed in detail through the CISAAD.[347] This council sets the minimum criteria for the whole state with respect to minimum carer-to-recipient ratios, staff qualifications, and the

[340] Jiménez, S. and Viola, A., *Observatorio de la Dependencia Tercer Informe: Estudios sobre la Economía Española – 2019/42*, FEDEA, Madrid, 2019. http://documentos.fedea.net/pubs/eee/eee2019-42.pdf
[341] Del Pozo, R. Pardo, I. and Escribano, F., 'El copago de dependencia en España a partir de la reforma estructural de 2012', *Gaceta Sanitaria*, 31(1), 2017, pp. 23-29; Jimenez and Viola, 2019.
[342] Montserrat Codorniu, J., *La Política Redistributiva de las Prestaciones de la Dependencia: Análisis del impacto del copago en las rentas de los usuarios*, Instituto de Estudios Fiscales, documentos de trabajo no 10/10, 2010.
[343] Montserrat Codorniu, J. and Montejo, I., *El Copago en la ley de Promoción de la Autonomía Personal y Atención a las Personas en Situación de Dependencia*, Fundación Caser, 2013. http://goo.gl/f8QjgY
[344] Spanish Official State Gazette (BOE), Resolution 13/7/2012.
[345] IPREM (public income indicator of multiple effects): EUR 537.84 per month.
[346] Montserrat Codorniu, J, 'La sostenibilidad del sistema de atención a la dependencia', *Papeles de Economía Española*, No 161, 2019.
[347] By means of the CISAAD, central government and regions agree on a framework for intergovernmental co-operation.

material resources/equipment/documentation applied to all accredited care centres.[348] Concerning informal carers, the common accreditation criteria in terms of training were regulated in 2009 by the CISAAD in order to guarantee the quality of care.[349] As for home-based and residential settings, the CISAAD also establishes essential quality standards for each of the services that make up the catalogue regulated under the 2006 law. In particular, common criteria are regulated for the entire state in terms of the intensity of protection of services, as well as the amounts of, requirements for, and conditions of access to, cash benefits.[350] Accredited centres can be inspected at the request of a dependent user or randomly by the autonomous community.

Dependency care is integrated into the social services system and, therefore, the definition of quality inherent in social services legislation prevails, while respecting the general framework of LAPAD. Given that the regional authorities have exclusive competences with regard to social services, and that dependency care is integrated into the regional systems of social services, the result is that in practice national legislation is adapted by regional legislation on social services. As a result, we observe a broad diversity among regulations and quality plans.

(b) The formal quality controls of the LTC system (the SAAD) are based on the accreditation systems established by each regional authority. Although there is a common denominator among them, based on LAPAD, each region has its own specific regulation and quality plan. In all of them it is compulsory to apply quality standards in the public service network and in the private network contracted by the public administration. This accreditation is usually based on the achievement of quality certificates in terms of infrastructure, periods of care, and staff training. The evaluation by the public sector of the quality of the non-professional or family care dependency benefit is practically non-existent or is not published. There is no published evidence on any evaluations of informal care conducted by the regional public sector. Only a few non-governmental organisations in the area of dependency are developing systematic projects to evaluate informal care, in the Basque Country,[351] Madrid, and Valencia.[352]

(c) With regard to good practices, the CISAAD agreed on common criteria to define, develop, and evaluate good practices in 2011. This agreement took the form of an IT tool to identify, plan, develop, and disseminate good practices in the application of the LAPAD. This

[348] Resolution of 2 December 2008, on common criteria of accreditation to guarantee the quality of centres and services for autonomy and dependency care. https://goo.gl/mroLSn. Regulation modified in 2015 (16 November 2015) (https://goo.gl/kkD9Co) and 2017 (30 December 2017) in order to update the professional qualifications and quality of care (https://goo.gl/E4mt9o).
[349] Resolution of 4 November 2009 on an agreement of the CISAAD on common criteria for training and information of non-professional care. https://goo.gl/TMDgjr.
[350] Royal Decree 727/2007, of 8 June, on criteria for determining the protection intensities of services and the amount of economic benefits of Law 39/2006. http://bit.ly/2lYe6GH. This Royal Decree has been updated by Royal Decree 175/2011, of 11 February; by Royal Decree 570/2011, of 20 April; by Royal Decree 1051/2013, of 27 December. http://goo.gl/rbKBsI and by Royal Decree 291/2015, of 17 April. http://goo.gl/qEEZwq. As evidenced in the 2018 ESPN Thematic Report, RD 1051/2013 reduced the intensity in the provision of services. Home-help services were one of the hardest hit, with a reduction of between 10 and 20 hours of care per month for people with the highest degree of dependency and 10 hours per month for severe and moderate degrees, all of which led to a reduction in the quality of care.
[351] Matia Foundation. http://bit.ly.
[352] Fundación Pilares, 2019.

agreement has not materialised over time, nor have most of the regions developed tools to evaluate good practices.[353]

## 2.3 Employment

### Workforce in LTC

On the one hand, according to the OECD,[354] there were 4.5 healthcare and social care professionals for every 100 people aged 65 and over in Spain in 2016, which gives us an estimated total of 410,000 professionals, of which 83.3 % were women. On the other hand, according to the labour force survey, the population employed in social services totalled 441,300 professionals at the end of 2019 (58 % in the non-residential services sector), part of them in the dependency sector. According to AEDGSS (2019), it is estimated that there were 260,850 direct jobs associated with the LAPAD in Spain in 2019.[355] This is an estimate since there is a significant volume of employment in social services associated indirectly with the dependency system.[356] According to different methodologies, the working population directly associated with the social LTC system would therefore range from 260,000 to 287,000 people.

However, the quality of employment is one of the more negative features of the SAAD. A pioneering study in 2008[357] assessed LTC employment as a precarious sector, with low levels of remuneration, high psycho-social risks, and insufficient training. These features seem to have persisted; according to more recent studies,[358] the part-time employment rate has been growing steadily since 2007 (22 %) and is currently at 32 % of the total population employed in social services. However, 30 % of all workers in residential services, and an even higher proportion of those in non-residential services, are on short-term contracts.

The challenge to those seeking employment in the LTC sector is to acquire the set of qualifications required according to the different professional profiles. All professional carers have been required to hold an intermediate professional training qualification, or a certificate of professionalism, since 2015. The insufficient supply of training and the lack of plans for professional accreditation hampered the goal of having all staff qualifications accredited by 2015. In 2018, the process of accrediting workers and companies in the LTC sector was completed. Between 2010 and 2019, 132,320 professionals in this sector were accredited. From 1 January 2018, all workers must be accredited in the different skills required by the SAAD.

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[353] Leturia, M., Zalakain, J., Mendieta, A. and Corcadilla, A., *Modelos de gestión de la calidad en la atención a las personas en situación de dependencia*, Donostia: SIIS, 2019.
[354] OECD, *Ensuring an Adequate Long-Term Care Workforce*, Paris, 2019.
[355] There is no specific heading in the national code of economic activities (CNAE) identifying the activities of LTC. They fall under two more general headings: assistance activities in residences and social services without accommodation. Obviously, LTC employment is a part of employment in social services.
[356] Martín-Serrano, E., 'Es todavía posible un sistema de dependencia como motor económico y de empleo?', *Actas de la Dependencia*, 11, 2014, 29-56.
[357] Aragón, J., Cruces, J. and Rocha, F., *Las Condiciones Laborales en el Sector de Atención a las Personas en Situación de Dependencia: Una aproximación a la calidad del empleo*, Fundación 1º de Mayo, 2008.
[358] *Cuadernos de Información Sindical: El sistema de protección social en España 2018,* Madrid: Confederación Sindical de Comisiones Obreras, 2019. https://www.ccoo.es/42ea0c6c33b835bc1a4e468e110ab133000001.pdf.

**Informal care**

Informal care is central to the system of care for dependent people. The share of the population providing informal care was 11.5 % in 2016 (EU-27: 10.3 %), 13.3 % of women and 9.5 % of men; 80.3 % of informal care-givers aged over 65 were women (EU-27: 90.8 %) (OECD 2019). 52.9 % of informal carers provided more than 20 hours of care per week (57 % women, 47 % men) (EU-27: 22 %), representing almost three hours per day of work which, in general, is unpaid.

Non-professional care was regulated in 2009 in order to guarantee its quality[359] under the family care cash benefit arrangements, but in practice there has been little or marginal progress.

Women are the main informal carers of dependants in Spain. Historically, they have shouldered the burden of care.[360] Despite cultural changes, new attitudes, and relative advances in the distribution of the care-giving burden, women continue to assume the responsibility and the bulk of care-giving.

Informal care reduces the opportunities for participation in the labour market. Besides, employment opportunities remain insufficient for older women carers, who find themselves in the unwanted position of having to accept part-time jobs. As noted in a 2016 report,[361] the most significant problem is the lack of labour activity for women caring for family members, due to cultural reasons, because there is a lack of public services for dependent people, or because of an inability to pay for them. The proportion of women not in active employment is high, reaching nearly half the total (46 %).

Despite its importance, the supply of training for informal care-givers is still scarce and varies between the autonomous communities. Respite services, such as night centres, are one of the SAAD benefits.[362]

According to the OECD, about 22 % of workers in the LTC sector are immigrants (OECD 2019). The number of foreign workers who informally care for dependent people in the home to support, or replace, direct family members, is estimated at 170,900, which represents 12.7 % of the informal care population. The immigrant workforce will continue to grow in the

[359] BOE, *CISAAD agreement on common criteria for training and information of non-professional care*, 27 November 2009. https://goo.gl/TMDgjr). BOE, *CISAAD agreement on improving the quality of monetary benefits for family carers,* 16 March 2010. BOE, *On common criteria of accreditation to guarantee the quality of centres and services for autonomy and dependency care*, 17 December 2008; Regulation modified in 2015 (BOE 16 November 2015) and 2017 (BOE 30 December 2017) in order to update the professional qualifications and good-quality care.

[360] Durán, M.A., 'La otra economía española', in Torres C. (co-ord.), *Informe sobre la Situación Social de España 2015*, Madrid: CIS, 2015, pp. 472-485; Martínez-Buján, R., 'Los modelos territoriales de organización social del cuidado a personas mayores en los hogares', *Revista Española de Investigaciones Sociológicas,* Vol. 145, 2014, pp. 99-126; Martínez Buján, R. and Martínez Virto, L. (co-ords), *La Organización Social de los Cuidados de Larga Duración en un Contexto de Austeridad y Precariedad*, Zerbitzuan, 60, 2015. https://bit.ly/35l7GEx).

[361] Rodríguez Cabrero, G., Arriba, A., Marbán, V., Montserrat Codorniu, J. and Moreno-Fuentes, F.J., *ESPN Thematic Report on Work-life balance measures for people of working age with dependent relative: Spain,* European Social Policy Network (ESPN), European Commission, Brussels, 2016. https://goo.gl/LK5fRv); Bouget, D., Spasova, S. and Vanhercke, B., *Work-life Balance Measures for Persons of Working Age with Dependent Relatives in Europe. A study of national policies*, European Social Policy Network (ESPN), European Commission, Brussels, 2016.

[362] There is no national information on the volume of informal care-givers receiving homecare training. Regarding night centres, the information is aggregated with daycentres.

LTC system in the future, taking into account the projected increase in the dependent population and changes in family structure.

## 2.4 Financial sustainability

Expenditure on LTC varies according to whether we consider only expenditure on social services or if we include healthcare expenditure associated with dependency.

The 2021 Ageing Report[363] measures expenditure which in principle should include both components at around 0.7%, based on the System of Health Accounts classification.

AEDGSS (2020) states that social public expenditure per se was around 0.71 % of GDP in 2019. The report of the Commission for the Analysis of the Situation of Dependency estimated the cost of the SAAD at around EUR 6.9 billion in 2012, EUR 7.4 billion in 2015, EUR 8 billion in 2016 (0.72 % of GDP), and EUR 8.6 billion in 2017 (0.74 % of GDP). The projected subsequent cost of the SAAD would be EUR 9.3 billion in 2018 (0.77 % of GDP), EUR 10.2 billion in 2019 (0.82 % of GDP), and EUR 11.3 billion in 2020. The financing of the total cost of the SAAD was distributed as follows: 63.7 % by the regional authorities, 15.6 % by central government, and 20.7 % by out-of-pocket payments (AEDGSS, 2020). This estimate is generally shared by the different experts.

There were also differences between the regions with regard to the estimated public spending per dependent person receiving care in 2019. The national average was EUR 6494 and varied significantly between regions: EUR 4404 in Ceuta and Melilla, and EUR 5038 in the Balearic Islands, compared with EUR 7298 in the Basque Country (AEDGSS, 2020). According to Jiménez and Viola (2019), the contribution of the regions varied between 62 % (Galicia, Extremadura, Andalusia) and 73 % (Cantabria).

Some studies (Montserrat, 2013 and 2019; Prada Moraga and Borge González, 2015; Oliva Moreno, 2014) emphasise the need not only to recover the expenditure lost during the period 2012-2015,[364] but also to make a financial effort to respond to the growth of the dependent population, the challenge of providing an adequate quality of care, and the need to improve the quality of employment. Otherwise, the cost of care would revert to households, and the burden of care would fall primarily on women.

Compared with LTC spending of 0.7 % of GDP in 2019, the forecast is that spending will increase to 0.9 % (reference scenario) and 1.0 % (risk scenario) by 2030, according to the 2021 Ageing Report. This expenditure growth would not put the sustainability of the LTC system at risk. In the very long term (i.e. by 2050), the projected increases are more striking, at 1.3 % (reference scenario) and 2.1 % (risk scenario). This will depend not only on life expectancy (22.0 years at age 65, in 2019), but also (above all) on the ability to increase healthy life expectancy, which was 11.4 years in 2018.

[363] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

[364] Recovering the spending cuts for the period 2012-2015 would mean an increase of 0.5 % of GDP in LTC spending.

Improvements in efficiency and effectiveness have remained inadequate due to: the limited scale of the development of homecare and community-based services; insufficient co-ordination between social care and healthcare services; and the limited dispersal of innovative approaches to LTC, especially the models and practices of comprehensive and people-centred care, which are undergoing a broad development in Spain.[365]

[365] *Escenarios de Futuro de la Atención Integrada y Centrada en la Persona*, Estudio Delphi, Madrid: Sociedad Española de Geriatría y Gerontología, 2017.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

As of 31 December 2019, the number of people aged 0-64 who were beneficiaries of cash benefits and services totalled 305,823 (27.4 % of the total beneficiary population). Almost half of this group was aged 46-64. These are generally people with mental or physical disabilities. One of the benefits designed for this group is the personal assistant benefit, especially for working people.

The SAAD is a universal coverage system. However, it faces two problems. The first refers to coverage, especially in the case of 'rare diseases'. The second is that of affordability: that is, the adaptation to the special care needs that new forms of dependency require, especially mental illness.

# 3 REFORM OBJECTIVES AND TRENDS

There were no major reforms to the SAAD between 2017 and 2020, except for one measure under Royal Decree-law 6/2019,[366] whereby the government has paid for the social contributions of homecarers since April 2019.[367] Until 2012 the government paid for the contributions of informal carers who were recognised as care-givers in the ICP. Since July 2012 (Royal Decree 20/2012[368]) social security contributions for homecarers were suspended but they could subscribe to voluntary insurance in the social security system with reduced contributions.

Reforms to the Spanish system of dependency occurred mostly between 2012 and 2015. They generally involved adjustments in access, affordability, and financing. They gave primacy to reducing the cost of services, and led to an increase in co-payments by families, to the detriment of quality requirements. This situation has persisted almost to the present day (AEDGSS, 2019). The changes introduced included the following measures: a reduction of 15 % in the amount of the cash benefit for homecare; a delay in incorporating people with moderate dependency within the LTC system until July 2015; a reduction in the quantity of hours for home assistance; the suspension of social security contributions for homecarers (mentioned above); and a new information system and LTC expenditure justification system for the regions. This has resulted in a reduced intensity of the services and greater incompatibilities between cash benefits and services.

Due to the pandemic, the hiring of workers in the field of social services has been made more flexible for a period of three months, so that it is possible to hire people on the basis of proven experience in care for dependent people, and others who are in the last year of professional studies as a care-giver.[369]

[366] http://bit.ly/2KjiYBu
[367] There was also a draft state budget law for 2019, which established an increase of EUR 415 million in the funding of the SAAD, but the budget was not approved, and this led to a general election in April 2019.
[368] Royal Decree-law 20/2012, of 13 July. http://goo.gl/VQDLZ.
[369] Order SND/295/2020, of 26 March 2020. https://bit.ly/3co9jmq and the resolution of 23 March 2020, CISAAD agreement on common criteria of accreditation to guarantee the quality of centres and SAAD care. https://bit.ly/3gHcCZv.

On January 15th 2021, the CISAAD unanimously approved a Dependency Shock Plan 2021-23, whose main elements are:

- An increase in the financing of the SAAD by the General Administration, which has been specified in the increase in the amounts of the minimum level and the recovery of the agreed level included in the National General Budgets for 2021. There is a budget increase of 623 million euros for 2021 and the commitment of similar amounts for the next 2 years.
- An agreement so that this increase in funding will be dedicated to the adoption of specific SAAD improvement measures aimed at three objectives: a) substantially reduce the waiting list and waiting times; b) ensure adequate working conditions for people who work in the SAAD; and c) introduce improvements in services and benefits to guarantee adequate care for dependents.
- A timetable for the progressive introduction of these measures throughout the three years that the Shock Plan will last, prioritizing those that are more urgent and that can be applied more immediately, and with an adjusted estimate of its cost.
- The combination of these immediate actions with a medium-term strategic vision of the reforms required by the SAAD and of the changes that need to be promoted in the LTC model. For that purpose a full evaluation of the LTC system will be conducted, being its terms of reference already designed and under discussion. This will be followed by a profound reform of the SAAD according to the evidence and reccomendations provided by the evaluation.

During 2020, the Covid-19 pandemic has revealed and amplified many of the system's weaknesses, but it has also accelerated the reforms that have materialized in the Dependency Shock Plan agreements with the Territorial Council and with the Social Dialogue Table (employers and unions).

At the same time, the Spanish Government has presented to the European Commission, within the framework of the Next Generation program, a social component (component 22): emergency plan for the care economy and reinforcement of inclusion policies.

It contains important structural reforms for LTCs: reinforce the attention to dependens and promote the change of model of LTC; and to modernize the public social services establishing a new legal naframework with a national scope.

Investments are aimed to finance new infrastructure and services adequate to the new model and aimed to progress on de-institutionalisation and promote a person-centered model.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The Spanish LTC system has fostered a positive development of the social protection system. Its implementation coincided with the economic and financial crisis and, consequently, the fiscal consolidation policies implemented between 2012 and 2015 have hindered its

expansion and financing. The social demand for dependency benefits will continue to grow in the coming years.

Attempts to improve the effectiveness of the Spanish LTC system faces crucial challenges, faced with the rapid future growth of the dependent population aged over 65 and, at the same time, changes in the social structure of the informal care-giving population. These challenges are set out below.

(a) With regard to **access and affordability**, it will be necessary to reduce the long waiting lists for access to services and to expand the supply of homecare and community services, which are in high demand and very cost-effective; to integrate the cash benefit linked to a service into the system of private social service provision contracted out by the public sector, in order to guarantee its control; to make homecare and community-based benefits more flexible and compatible; to further develop the SAAD in rural areas; to standardise the criteria for co-payments existing in the different regions; and to implement people-centred care models that allow for the integration of social care and healthcare, residential and family care, with a greater participation by dependent people.

(b) In relation to the **quality of services**, especially the quality of formal employment, home-based care (covering 30 % of all recipients of dependency benefits) should be monitored for its quality and carers should be able to access training services. Strengthening social policies and benefits to reconcile the care for dependent people with formal employment remains a challenge in Spain.

(c) Ensuring the sustainability of the LTC system requires not only increasing social investment in LTC through an increased fiscal effort but also improving the **co-ordination** between the central and the regional administrations, and between the latter and the municipalities. The differences in performance between the regions are excessive and generate inequalities in the coverage and intensity of social protection. There is broad agreement that the financial commitment of central government should be increased, as it currently only amounts to 20 % of the total cost. At the same time, the current minimum guaranteed level of funding should be changed from a fixed amount per degree of dependency to a function of the real cost of services.

(d) Due to fiscal consolidation policies implemented from 2012, public spending on LTC was frozen. There is broad political agreement on the need to increase spending to meet demand for years to come.

# 5 BACKGROUND STATISTICS

| *5.1. Demographics* | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 45.7 | 46.9 | 48.7 | 49.3 |
| Old-age dependency ratio, 2019 | | 23.8 | 29.5 | 37.2 | 59.5 |
| Population 65+ (in millions), 2019 | Total | 7.5 | 9.1 | 11.6 | 16.1 |
| | Women | 4.3 | 5.2 | 6.5 | 8.9 |
| | Men | 3.2 | 4.0 | 5.1 | 7.2 |
| Share of 65+ in population (%), 2019 | | 16.4 | 19.4 | 23.8 | 32.7 |
| Share of 75+ in population (%), 2019 | | 8.2 | 9.6 | 11.6 | 18.9 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 20.9* | 22 | | |
| | Women | 22.9* | 23.9 | 24.6 | 26.2 |
| | Men | 18.6* | 19.8 | 20.7 | 22.5 |
| Healthy life years at the age of 65, 2018 | Total | 9.3* | 11.4 | | |
| | Women | 9.1* | 11.3 | | |
| | Men | 9.6* | 11.5 | | |

**data for 2010*

| *5.2. People in need of LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 2,006.8 | 2,315.7 | 2,915.7 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 1,214.4 | 1,502.6 | 2,264.7 |
| | Women | | 792.1 | 960.4 | 1,430.7 |
| | Men | | 422.3 | 542.2 | 834.1 |
| Share of potential dependants in total population (%), 2019 | | | 4.3 | 4.7 | 5.9 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 13.2 | 12.8 | 14.0 |
| Share of population 65+ in need of LTC** (%), 2019* | | 34.0 | 28.8 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| *5.3. Access to LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 1.2 | 1.2 | 1.4 |
| Share of population 65+ receiving care at home (%), 2019 | | | 3.9 | 3.8 | 4.4 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 4.4 | 4.3 | 5.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 38.9 | 38.5 | 41.3 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 33.4 | 33.2 | 35.6 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 49.7 | 47.9 | | |
| | Women | 52.8 | 49.5 | | |
| | Men | 41.5 | 43.6 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 12.4 | 10.8 | | |
| | Women | 15.4 | 13.3 | | |
| | Men | 8.6 | 7.5 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 54.1 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 7.3 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 813.1 | 830.3 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 4.2 | 4.5 | | |
| | % Women | | 80.3 | | |
| Share of population providing informal care (%), 2016 | Total | | 11.5 | | |
| | Women | | 13.3 | | |
| | Men | | 9.5 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 52.9 | | |
| | Women | | 57.0 | | |
| | Men | | 47.0 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.0 | 0.7 | 0.9 | 1.3 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.0 | 0.7 | 1.0 | 2.1 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 50.6 | 50.2 | 49.9 | 50.9 |
| Public spending on home care as % of total LTC public spending, 2019 | 17.7 | 25.9 | 27.0 | 27.3 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 31.7 | 23.9 | 23.1 | 21.8 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.7 | 0.7 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.1 | 0.1 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.2 | 0.1 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.0 | 0.0 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# FRANCE

## *Highlights*

- 23.9 % of the French population will be aged 65 or over in 2030. Based on the French long-term care (LTC) indicator (the number of people aged 60 or over who receive the personal autonomy allowance[370]), the estimated number of LTC recipients will increase from 1,265,000 in 2015 to 1,582,000 in 2030 and 2,235,000 in 2050, which is an overall growth for 2015-2050 of 76 %.
- LTC public expenditure, representing 1.7 % of GDP in 2017 (currently estimated at EUR 23.7 billion – national data), constitutes a major, although fragmented, financial investment in France, and could reach 2.1 % of GDP by 2030. These data concern LTC for people with disabilities and dependent older people. Expenditure specifically relating to LTC for older people was around EUR 11.3 billion in 2018.[371] In addition, the cost of informal care has an estimated value of EUR 7-18 billion.
- Improving access and affordability in relation to LTC services is a major concern that is managed by reducing out-of-pocket expenditure and developing co-ordination between the healthcare and social care sectors.
- Despite real investment in developing a specific social care employment sector, a key challenge facing France today is the reorganisation of the LTC workforce.
- Since legislation on adapting society to an ageing population of December 2015, no comprehensive LTC reforms have taken place in France. However, the major guidelines of a deep-seated reform, announced for 2021, were presented in the Libault report of 2019, which includes a recommended investment of almost EUR 10 billion in LTC by 2030. The first step in this major reform was the law of 7 August 2020 on social debt and autonomy,[372] which creates a fifth area of the national health service, dedicated to dealing with the loss of autonomy of older people and people with disabilities, with a EUR 1 billion funding project.

[370] Allocation personnalisée à l'autonomie – APA.
[371] Les Dépenses de Santé en 2018: Résultats des comptes de la santé – 2019 edition, Direction de la Recherche, des Etudes, de l'Evaluation et des Statistiques (DREES), 2019. https://drees.solidarites-sante.gouv.fr/sites/default/files/2020-07/cns2019.pdf.
[372] Decree no 2020-998. https://www.legifrance.gouv.fr/loda/id/JORFTEXT000042219614/2020-09-13

# 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

## 1.1 Demographic trends

In 2019, the old-age-dependency ratio in France was 32.5 and is set to reach 40 % in 2030 and 49.3 % in 2050, according to EU-27 estimations of fertility rates and life expectancy at birth.[373] This scenario is somewhat debatable. For example, it assumes a stable fertility rate of two children per woman for the next 30 years, which is not the trend observed at national level (a slow but regular fall from 2.03 in 2010 to 1.87 in 2017).[374]

In 2019, 13.5 million people were aged 65 and over (7.7 million women and 5.8 million men), representing 1 in 5 of the total population (20.1 %). Projections for the next decades are as follows: in 2030, the population aged 65 and over would represent 23.9 % of the total population (16.4 million – 9.2 million women and 7.2 million men); in 2050, the figure would be 19.4 million (10.9 million women and 8.5 million men), representing more than one quarter (27.7 %) of the total population. This is below the EU-27 average of 29.3 %. These calculations take into account the evolution of life expectancy at age 65. In 2019, life expectancy at 65 was 21.9 years (23.8 for women and 19.7 for men), while healthy life expectancy was 10.8 years (11.3 for women and 10.2 for men). This was above the EU-27 average, which was 20 and 9.9 respectively.

In addition to these estimates, two other trends are of interest: the first one is a slowdown in the gain in life expectancy at birth over the last decade, notably due to three major influenza epidemics from 2014 to 2019, each of which generated around 20,000 registered deaths; and the second important issue concerns socio-economic inequalities in life expectancy. For example, the difference in life expectancy at birth between the richest 5 % and poorest 5 % men is 13 years (8 years for women).[375]

Concerning the very old population, the share of those aged over 75 in the French population is growing much more rapidly: from 9.4 % in 2019 to 12.5 % in 2030, and 16.3 % in 2050. In the light of demographic trends, the estimated number of potentially dependent older people[376] will grow from 3,268,000 in 2019 to 3,975,000 in 2030 and 5,188,000 in 2050. In 2019, 4.9 % of the population aged 65 and over in France received care in institutions, 6.2 % at home (none received cash benefits), which means that 11.1 % of this age group received formal in-kind LTC benefits.

The French LTC system is based on a different age threshold related to the granting of the APA (personal autonomy allowance – *Allocation personnalisée à l'autonomie*) to people aged

[373] All data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.
[374] This report does not take into account the impact of the current COVID-19 pandemic, which will surely lead to important measures.
[375] Blanpain, N., *L'Espérance de Vie par Niveau de Vie: Chez les hommes, 13 ans d'écart entre les plus aisés et les plus modestes*, Insee Première, No 1687, 2018.
[376] The potentially dependent population refers to EU-SILC data on 'self-perceived longstanding limitation in activities because of health problems [for at least the last 6 months]'. See: European Commission, *The 2018 Ageing Report: Economic and budgetary projections for the 28 EU Member States (2016-2070),* European Commission, Brussels, 2018. https://bit.ly/2KAqG8r.

over 60. The estimated number of recipients for this allowance is likely to increase considerably: from 1,387,000 in 2020 to 1,582,000 in 2030 and 2,235,000 in 2050.[377] Taking into account older people who do not receive the allowance, the DREES estimates that about 1,459,000 people aged over 60 living at home were subject to loss of autonomy in 2015, in addition to 584,000 people living in care homes, making a total of over 2 million.

## 1.2 Governance and financial arrangements

Traditionally characterised by a familialist approach to care for older people, with a legal obligation for families to care for their older parents, since the 1990s France has developed several LTC policy measures and evolved towards a mixed model, combining public measures and family care.[378] LTC policy in France cuts across different policy sectors – health, social, and medico-social[379] – and involves several levels of governance: the state, regions, *départements*, and municipalities. Regional administrations implement national health policies defined centrally by the government, whereas the decentralised local authorities – *départements* – are responsible for social policy. They have a key role in LTC regulation: they define local policy orientations in their areas; finance and manage the national APA; and regulate care services. Though some territorial disparities exist, different social care schemes are defined in national legislation, and territorial variations are monitored by the government (Libault, 2019). In addition, municipalities can develop specific voluntary support measures. Along with this territorial organisation, two major institutional actors are involved. The first is the CNSA (national solidarity fund for autonomy – *caisse nationale de solidarité pour l'autonomie*), created in 2004, which is a national institution responsible for implementing policy measures aimed at older people and people with disabilities.[380] The second is the regional health agencies (*agences régionales de santé* – ARS), introduced in 2009; they are the regional representative of central government, extending regional intervention to the social care sector (traditionally limited to healthcare).

LTC involves a wide range of funding (social security system, the *départements*, the CNSA, and central government) for wide-ranging expenditure, combining the health insurance system and a tax-based system for funding the APA. In 2017, LTC public spending represented 1.7 % of GDP. Considering national data, and taking into account costs covered by households, LTC represented 1.4 % of GDP in 2014; it thus constitutes a major, though fragmented, financial investment in France.[381] The cost of informal care accounts for almost

[377] Libault, D., *Grand âge et autonomie* [Old age and autonomy], Ministry of Solidarity and Health, 2019. https://solidarites-sante.gouv.fr/IMG/pdf/rapport_grand_age_autonomie.pdf.
[378] Le Bihan, B., Da Roit, B. and Sopadzhiyan, A., (2019), 'The turn to optional familialism through the market: long- term care, cash- for- care, and caregiving policies in Europe', *Social Policy and Administration*, Special Issue Cash for Care in Europe, pp. 579-594.
[379] A specifically French sector: common English usage only distinguishes 'healthcare' and 'social care' sectors.
[380] The funds of the CNSA combined different sources: a transfer of part of the sickness branch of the social security system (EUR 20.4 billion); taxes (EUR 2.7 billion); a social contribution – (EUR 2.4 billion).
[381] Roussel, R., 'Personnes Agées Dépendantes: Les dépenses de prise en charge pourraient doubler en part de PIB d'ici à 2060' [Dependent older people: care expenditure as a share of GDP could double by 2060], *Etudes et Résultats* No 1032, DREES, 2017. https://drees.solidarites-sante.gouv.fr/IMG/pdf/er1032.pdf.

an additional EUR 15 billion, on top of other imputed costs borne by households (housing, dependency).[382]

## 1.3 Social protection provisions

Different schemes can be distinguished, each with its own characteristics depending on the system (healthcare or social care) it comes under.

**A first group of schemes corresponds to 'social assistance schemes' which are managed by *départements* and/or pension funds**

- Social assistance for accommodation:[383] paid out by the *départements* to people aged 65 and over with low incomes living in institutions, to make up for accommodation costs which cannot be paid for by the resident.[384]
- Financial support to pay for home-helps: granted by the *départements* and pension funds depending on the age and income of old people with the lowest level of dependency.

**The cornerstone of social care policy is a specific policy measure: the APA**

Introduced in the late 1990s and focusing on situations of dependency, the benefit was aimed at meeting the needs of older people who were not covered by health insurance, by helping them identify their needs and pay for social care services. It was reformed in 2002 and became the APA. Managed by the *départements*, the APA is paid – at home or in institutions – to anybody aged 60 or over who needs assistance to accomplish everyday activities or who needs to be continuously watched over. Each level of dependency – according to the AGGIR grid[385] – gives access to a maximum amount, which is then adjusted according to the recipient's needs and level of income. In 2020, for GIR 1 dependency level the maximum amount of the allowance was EUR 1742.34; for GIR 2, EUR 1399.03; for GIR 3, EUR 1010.85; and for GIR 4, EUR 674.27.

For those cared for at home, the allowance is paid to finance a specific 'care plan' elaborated by a multidisciplinary team (healthcare and social care professionals from the *départements*) after an assessment of needs. The use of the benefit is controlled and the multidisciplinary teams are in charge of follow-up action. The APA represents over EUR 5 billion of expenditure, of which 65 % comes from the *départements* and 35 % from the CNSA.[386] The APA was allocated to 1,285,500 older people in December 2016 (7.6 % of people aged over 60), of whom 60 % were cared for at own home and 40 % in residential settings.

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[382] Ennuyer, B., 'Quel avenir pour les personnes dites 'âgées' ayant besoin d'aide et de soins dans leur vie quotidienne', in Guillemard A.-M. and Mascova E. (dir.), *Allongement de la vie. Quels défis ? Quelles politiques ?* Paris, La Découverte, 2017, pp. 279-295.

[383] *Aide sociale à l'hébergement* – ASH.

[384] The allowance is delivered to people with an income (household's income plus – in some *départements* – the income of close relatives) below the cost of accommodation. According to DREES, there were 122,000 recipients of the ASH in 2017, with an amount of around EUR 870 per month. 92 % of recipients lived alone, and 50 % had an income below EUR 900 per month.

[385] The *Autonomie Gérontologie Groupes Iso-Ressources* (AGGIR) grid distinguishes six levels of dependency, from *groupe iso-resource* (GIR) 1 (highest) to GIR 6 (lowest). For detailed information, see: https://www.service-public.fr/particuliers/vosdroits/F10009.

[386] *Les Chiffres Clés de l'Aide à l'Autonomie 2019* [Key figures on support for autonomy], CNSA, 2019.

Employing a care worker in the home also opens up the right **to fiscal deductions** and, since 2017, **tax credits**.

**A final category of schemes concerns informal carers,** in two different forms, as follows.

- Carer's leave: allocated for three months or a part-time period, renewable up to one year. Financial compensation was also approved in October 2019 (EUR 42-55 per day from October 2020).
- Family solidarity leave to assist a dying relative: allocated for three months, renewable once and can be used on a part-time basis. Daily allowance of EUR 55 for a maximum of 21 days.

## 1.4 Supply of services

A wide range of services in the social care and healthcare sectors support both homecare and residential care, as well as supplementary options. They depend on different regulations (related to healthcare or social care systems), which create financial and administrative complexity.

**Homecare nursing services**[387] and **home social care and healthcare services**:[388] 125,733 places in 2019 (CNSA, 2019). Healthcare services are provided by salaried nurses and auxiliary nurses paid on a fee-for-service basis. Total expenditure on this type of care rose by 2.7 % in 2017, amounting to about EUR 1.6 billion.[389]

**Home-help and support services**:[390] these constitute a highly complex sector[391] including non-profit organisations and public social care services requiring quality certification by the *départements*. Based on an analysis of APA recipients, their number was estimated at 7000.

**Private for-profit organisations in the personal services sector**: requiring specific quality certification. Their prices are established freely. In 2008, they represented only 4 % of social care workers for older people.[392]

**Residential homes** (or 'EHPADs'[393]): France has 7438 EHPADs, offering 98 places per 1000 people aged 75 and over.[394] In 2015, these institutions cared for 10 % of older people aged 75 or over, and one third of those aged 90 or more. The average cost of EHPAD accommodation

[387] *Services de soins infirmiers à domicile* – SSIAD.
[388] *Services polyvalents d'aide et de soins à domicile.*
[389] DREES, *Les Dépenses de Santé en 2017* [Health expenditure in 2017], 2018. https://drees.solidarites-sante.gouv.fr/IMG/pdf/32-7.pdf.
[390] *Services d'aide et d'accompagnement à domicile* – SAAD.
[391] El Khomri, M., *Plan de Mobilisation Nationale en Faveur de l'Attractivité des Métiers du Grand Age* [National plan to make work for older people more attractive], Ministry of Solidarity and Health, 2019. https://solidarites-sante.gouv.fr/IMG/pdf/rapport_el_khomri_-_plan_metiers_du_grand_age.pdf.
[392] Marquier, R., 'Les Intervenants au Domicile des Personnes Fragilisées en 2008' [Workers providing support in the home for vulnerable people in 2008], *Etudes et Résultats* No 728, DREES, 2010. https://drees.solidarites-sante.gouv.fr/IMG/pdf/er728-2.pdf.
[393] *Etablissements d'hébergement pour personnes âgées dependants.*
[394] Bazin, M. and Muller, M., 'Le Recrutement en EHPAD' [Recruitment in nursing homes], *Etudes et Résultats* No 1067, DREES, 2018. https://drees.solidarites-sante.gouv.fr/IMG/pdf/er_1067.pdf.

ranges from EUR 51 to EUR 71 per day.[395] These institutions take different forms (Libault, 2019): private for-profit EHPADs (22 % of places), private not-for-profit EHPADs (28 % of places), and public EHPADs (50 % of places). The latter may or may not be hospitals. Despite an increase in staff-to-patient ratios between 2011 and 2015 – from 59.7 to 62.8 full-time equivalent (FTE) staff for every 100 patients (Bazin and Muller, 2018) – the number of staff remains insufficient to ensure good-quality care.

**Supplementary options developed between homecare and residential care:**

- **Housing facilities**: these concern old people who are mostly autonomous, and involve small apartments adapted to minimise the risk of falls. The development of this type of accommodation (renamed autonomous residences – *résidences autonomie*) is a priority under the 2015 'ASV' Act.[396] They offered 110,000 places in 2018 (CNSA, 2019).
- Autonomous residences and nursing homes offered 11,900 **daycare places** and 15,500 in **temporary accommodation** in 2018 (CNSA, 2019).

In 2015, 728,000 older people lived in residential care, an increase of 4.8 % compared with 2011 (Muller, 2017). The recent CARE survey [397/398] estimates the number as being between 0.4 million (including only high-level dependency cases) and 1.5 million (also including mid-level dependency cases). Concerning the balance between formal and informal carers, the CARE survey established that almost 50 % of older people in need of care receive support from their relatives, and 20 % only receive professional support. The remaining 30 % receive both formal and informal support.[399]

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

In 2019, 4.9 % of people aged over 65 were cared for in institutions compared with 6.2 % in their homes. Out-of-pocket spending varies according to whether care is provided at home or in a residential setting, as well as according to the level of dependency of the older people concerned. The share of user's disposable income spent on out-of-pocket costs is around 150 % for dependants with severe needs.[400] One month's accommodation in an EHPAD for

[395] Muller, M., '728 000 Résidents en Etablissements d'Hébergement pour Personnes Agées en 2015: Premiers résultats de l'enquête EHPA 2015' [728, 000 residents in old people's homes in 2015], *Etudes et Résultats*, No 1015, DREES, 2017. https://drees.solidarites-sante.gouv.fr/IMG/pdf/er1015.pdf.
[396] *l'Adaptation de la Société au Vieillissement*.
[397] *Capacités, aides et ressources des seniors* – CARE.
[398] Brunel, M. and Carrère, A., 'Les Personnes Agées Dépendantes Vivant à Domicile en 2015: Premiers résultats de l'enquête CARE 'ménages' [Dependent old people living at home in 2015: first results of CARE household survey], *Etudes et Résultats* No 1029, DREES, 2017. https://drees.solidarites-sante.gouv.fr/IMG/pdf/er_1029.pdf.
[399] Brunel, M., Latournelle, J. and Zakri, M., 'Un Senior à Domicile sur Cinq Aidé Régulièrement pour les Tâches du Quotidien' [1 old person in 5 living at home receives regular support for everyday tasks], *Etudes et Résultats*, No 1103, DREES, 2019. https://drees.solidarites-sante.gouv.fr/IMG/pdf/er1103.pdf.
[400] OECD, *Measuring Social Protection for Long-term Care in Old Age: Phase 2*, OECD Publishing, 2019.

someone with a radical loss of autonomy costs on average EUR 2450,[401] leaving EUR 1850 on average to be paid by the user (after allowances and tax reductions) (Libault, 2019). Although the APA covers 100 % of healthcare costs and about two thirds of 'dependency' costs, accommodation services are the responsibility of families (except those on very low incomes: see Section 1.3).

The question of cost is more difficult to value in the case of homecare. Depending on the income of the care recipient, the remainder to be paid can range from EUR 2500 to EUR 4050 in situations of high dependency, when a carer is required to be permanently present (Mutualité Française, 2018). However, these figures are different for old people benefiting from support from an informal carer in their homes. The remainder to be paid in this case depends on the level of dependency, and ranges from EUR 117 for a high level of dependency (GIR 1) to EUR 37 for an average level (GIR 4). This explains the average figure of EUR 60 remaining to be paid by old dependent people (after allowances and tax reductions) presented in the Libault report. Although this amount may seem acceptable, it raises the question of the significant amount of invisible, unpaid work carried out by informal carers, which enable this lower financial cost through maintenance in the home.

Fragmentation is a main characteristic of the French LTC field, with the separation between the healthcare and social care sectors. Improving the co-ordination of organisations, institutions, and professionals in order to facilitate access and affordability in relation to services/schemes has been high on the political agenda during the last decade. Since 2010, three different schemes have been developed with the objective of facilitating relations between the different actors at the local level: (a) the 'scheme for integrating health and support services in the autonomy field',[402] introduced in 2010 and concerning older people aged 60 and over with complex needs; (b) the 'old people at risk of losing their independence' scheme,[403] created in 2014, which is a specific health pathway combining a range of preventive tools targeting older people aged 75 and over; and (c) the 'territorial support platform',[404] which is not population-based. More recently the 'co-ordination support measure'[405] is aimed at gathering all of these existing schemes into one (see Section 3).

## 2.2 Quality

In France, no formal, comprehensive definition of LTC quality has been produced by national or local public authorities. Nevertheless, the Act of 2 January 2002 reforming the social care sector describes the different components of quality. Taking into account recent developments (ASV Act), three main dimensions can be identified, as follows.

a) The obligation for social care providers to carry out a double evaluation: an internal evaluation carried out by the provider and focused on quality improvement; and an

[401] Mutualité Française, *Santé, Perte d'Autonomie: Impact financier du vieillessement* [Health and loss of autonomy: financial impact of ageing], Place de la Santé, L'Observatoire, 2018. https://placedelasante.mutualite.fr/wp-content/uploads/2018/09/barometre-fnmf-1018_vf_180926.pdf.
[402] *Méthode d'action pour l'intégration des services d'aide et de soin dans le champ de l'autonomie* – MAIA.
[403] *Personne agée en risque de perte d'autonomie* – PAERPA.
[404] *Plateforme territoriale d'appui* – PTA.
[405] *Dispositif d'appui à la coordination* – DAC.

external evaluation (which guarantees renewed authorisation) carried out by an external body approved by the National Authority for Health (HAS),[406] which concerns their activities and the quality of the services they deliver.

b) The respect of different basic user rights: respect for dignity, integrity, private life, intimacy, and security; a free choice between services at home or in a residential setting; personalised, good-quality care and support that respects informed consent; confidentiality of user data; access to information; direct participation in the definition of the 'care and support project' – as well as tools enabling the exercise of these rights; the existence of a welcome booklet; respect for the charter of rights and freedoms of the person hosted; recognition of a qualified individual; visible operating regulations of the establishment or service; the existence of a 'community life council' which encourages user participation; and the production of an establishment or service project.

c) Multiannual contracts (five years) of objectives and means (CPOM[407]) – which were made general to all social care facilities by the ASV Act – are signed between social care providers and pricing authorities (ARS and *départements*).

The double evaluation process was questioned in a recent report,[408] which identified different elements for improving quality approach: a better articulation between the two evaluations, a harmonisation of the external bodies which produce evaluations; and a standardisation of the different indicators used for evaluations.

This issue is related to the employment issue and the very low appeal of the LTC labour sector. Recent solutions were proposed by the Libault report (see Box 1); for example, creating indicators to measure the quality of services available in residential homes.

## 2.3 Employment (workforce and informal carers)

It is difficult to estimate the number of professionals working with older people – both healthcare professionals (nurses and assistant nurses) and social care workers (also called personal carers) – because no statistics precisely list professionals in this highly fragmented labour sector. In terms of national data, the Libault report – which treats the LTC workforce as a key policy issue (see Box 1) – estimated that in 2018 about 830,000 FTE staff work with dependent older people (6.3 long-term care workers per 100 people aged 65 or more), including 430,000 in institutions, 270,000 in home social care services, and 130,000 in home healthcare services.

Qualifications are a key issue concerning the LTC workforce. As recalled in a recent OECD report,[409] in France qualifications are required for nurses (specific training after a bachelor's degree), and there is the possibility for personal workers to obtain a specific diploma (created

[406] Created in 2009, the National Agency for Evaluating the Quality of Social Care Institution and Services (ANESM) is now included in the National Authority for Health (HAS).
[407] *Contrat pluriannuel d'objectifs et de moyens*.
[408] Vidal, A., *Rapport d'Information sur l'Evolution de la Démarche Qualité au Sein des EHPAD et de son Dispositif d'Evaluation [Information report on the evolution of quality in residential care]*, No 1214, Assemblée nationale, 2018.
[409] OECD, 'Who Cares? Attracting and retaining care workers for the elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en.

in 2002). Continuing training programmes were also developed. In spite of this, the LTC care work sector remains unattractive.[410] The OECD report underlines the difficult working conditions of LTC workers, with France having the highest shares of LTC workers reporting accidents and work-related health problems. The difference between LTC workers and hospital workers is also highlighted, with the former earning less than the latter. The average wage of homecarers is EUR 832 per month, but monthly earnings vary significantly according to whether care workers are employed full time (EUR 1190) or part time (EUR 717), and whether the structure they belong to is public or private.[411] Employment conditions are another main issue. LTC workers work in shifts and work during weekends. The employment stability given by the existence of permanent contracts is only on the basis of a high prevalence of part-time work: in homecare, 23 % of nurses, 31 % of personal carers, and 42 % of LTC workers hold a part-time position (26 % in institutions) (OECD, 2020). Moreover, residential settings employ a high proportion of temporary agency workers (OECD, 2020).

The *ségur de la santé* reform of July 2020 grants an increase of EUR 183 per month to all public and private not-for-profit non-medical carers in residential homes (and EUR 160 per month for the private for-profit sector), amounting to 1.5 million professionals.

Finally, it should be noted that the specific social care work sector developed in France to provide personal care in the home (as a complement to the healthcare delivered by nurses and assistant nurses) is part of the larger sector of 'personal services' (*services à la personne*), which includes anyone providing services to individuals. Focusing on the volume of workers in order to reduce unemployment, it is not always matched by quality (Le Bihan and Sopadzhiyan, 2018).

In France, a large majority of older people currently receive informal support from families and friends – 21 % of the population aged 60 and over, representing 3 million older people (Brunel et al., 2019). 14.1 % of the population provide informal care: 16.3 % of women and 11.9 % of men. According to national statistics, 3.9 million informal carers[412] perform a great variety of concrete tasks (ADL provision,[413] meal preparation, personal care, etc.) and co-ordinate activities. Evidence shows that informal carers carry out more diverse tasks than professional care workers, who focus on instrumental tasks (Brunel et al., 2019). A recent survey shows that half of these carers are the children of the care recipient, and a quarter are spouses or partners (Brunel et al., 2019). Aged on average 73 for the latter and 52.2 for the former, most of them are women (59.5 %). 4 carers in 10 are in employment. Considering the

[410] Le Bihan, B. and Sopadzhiyan, A., 'The development of an ambiguous care work sector in France: between professionalization and fragmentation', in Christensen, K. and Pilling, P. (eds), *The Routledge Handbook of Social Care around the World*, Routledge, 2018, pp. 102-115.
[411] Nahon, S., 'Les Salaires dans le Secteur Social et Médico-social en 2011: Une comparaison entre les secteurs privé et public' [Pay in the social and medico-social sector in 2011 – comparison between private and public sectors], *Etudes et Résultats*, No 879, DREES, 2014. https://drees.solidarites-sante.gouv.fr/IMG/pdf/er879.pdf
[412] Besnard, X., Brunel, M., Couvert, N. and Roy, D., 'Les Proches Aidants des Seniors et leur Ressenti sur l'Aide Apportée: Résultats des enquêtes CARE auprès des aidants' *(2015-2016)* [Family care-givers of older people and their experience of support: results of CARE surveys of carers], *Les Dossiers de la DREES*, No 45, DREES, 2019, https://drees.solidarites-sante.gouv.fr/IMG/pdf/dd45.pdf.
[413] Activities of daily living.

increase in the labour market participation of women aged 50-64,[414] the issue of work-life balance is particularly acute for women.

In France, public interventions aimed at informal carers are based on 'supportive measures', defined as measures to assist carers in their role:[415] alongside the existing training available since a 2009 health law and the national web platform created in 2013, the ASV Act has introduced a right to respite, and created special centres for older people and their carers (see Section 3). Until recently, financial measures aimed at compensating informal carers remained marginal, with the possibility of using the APA to pay a relative (except the spouse). Only 8 % of APA beneficiaries pay a relative as their homecarer;[416] the recent approval of financial compensation to cover leave for the existing carer marks a turning point in the type of measures implemented (see Section 3).

## 2.4 Financial sustainability

Different factors have a bearing on the financial sustainability of LTC policy. One factor is demography (see Section 1.1). However, expenditure also varies according to the level and type of coverage of population needs; in particular whether France relies on formal or informal care, at home or in residential settings.[417]

According to the 2021 Ageing Report[418] projections, public expenditure on LTC in France is projected to increase in relation to GDP by 0.7 p.p. (or 37 %) between 2019 and 2050 (from 1.9 % in 2016 to 2.6 % in 2050) in the 'reference' scenario, based on the impact of an ageing population on public LTC expenditure.

Nevertheless, these projections depend on different policy options. The Ageing Working Group also considered an 'AWG risk' scenario, which is based on the assumption that half of the future gains in life expectancy are spent without a disability requiring care as in the reference scenario. In this scenario public expenditure on LTC will grow from 1.9 in 2019 to 3.7 % of GDP in 2050, which means an increase of 1.8 p.p., or 95 %.

National analyses of the cost of dependency have also been produced. Roussel (2017) estimates LTC costs at EUR 30 billion in 2014 (1.4 % of GDP), of which EUR 23.7 billion is covered by public expenditure (79 % of the total) and EUR 6.3 billion by households. Expenditure is split as follows: EUR 12.2 billion devoted to healthcare expenditure (EUR 12.1 billion public funding, EUR 0.1 billion by households); EUR 10.5 billion devoted

[414] Up to up to 61.2 % in 2017 according to: Institut National de la Statistique et des Etudes Economiques (INSEE), *Les tableaux de l'économie française* [French economy tables], 2019.
[415] Le Bihan, B. Lamura, G., Marczak, J., Fernandez, J.L, Johansson, L. and Sowa-Kofta, A., 'Policy measures to support unpaid care across Europe, in enhancing the sustainability of long-term care', *Eurohealth*, Vol. 25/4, 2019, pp. 10-14.
[416] Court of Auditors, *Le Maintien à Domicile des Personnes Agées en Perte d'Autonomie* [Maintaining old dependent people in their homes], 2016. https://www.ccomptes.fr/sites/default/files/EzPublish/20160712-maintien-domicile-personnes-agees.pdf.
[417] These elements generally appear in terms of level of coverage of the 'potentially dependent population' in terms of access to homecare, residential care, and cash benefits. The potentially dependent population refers to EU-SILC data on 'self-perceived longstanding limitation in activities because of health problems [for at least the last 6 months]': see European Commission, 2018.
[418] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

to coverage of loss of autonomy (EUR 8.3 billion public funding); and EUR 7.1 billion devoted to residential accommodation (including EUR 3.1 billion public expenditure and EUR 3.8 billion by households). To this can be added EUR 4.4 billion for 'board and lodging' (the cost of food, housing, and insurance paid for by households in residential care that they would have to cover in the home). However, this figure does not include the cost of informal care, which is estimated at EUR 7-18 billion. As argued by several studies, the expenditure related to care for older people is in fact equally shared between households and the public sector. Based on this data, the Libault report argues that a 35 % increase is needed in the share of national wealth devoted to dealing with loss of autonomy, which corresponds to public expenditure of about 1.6 % of GDP. A specific funding plan is proposed in the report (see Box 1).

### 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Specific key challenges can be identified regarding care for children and people with disabilities. An important issue arises from the policy to facilitate inclusion for people with disabilities in a 'normal environment',[419] which involves promoting and facilitating independent living. It concerns both encouraging the employment of people with disabilities in the public and private sectors and also facilitating schooling for children with disabilities. The professionalisation of special needs assistants who support children at school every day is a key dimension of this policy. The shift was initiated in 2013 with the introduction of a new profession – assistants for pupils with disabilities[420] – selection for which requires a higher level of education (at least *baccalauréat* or equivalent) and specific training. This was followed up by the creation of a state educational and social assistance diploma.[421] Another important step is the establishment of a personalised plan for each child included in a specialised local unit for inclusion in schools,[422] which is linked to an ordinary school. Another issue in the field of LTC care concerns the reform of the pricing of residential care and medico-social services working with people with disabilities. This vast project was initiated in 2015 and is still underway.

## 3 REFORM OBJECTIVES AND TRENDS

The major guidelines of a deep-seated reform were presented in a report dating from March 2019 – the Libault report (see Box 1). Initially announced for 2019, the old age and autonomy plan was delayed. However, in the context of the COVID-19 crisis and considering the strong impact of it on older people at home and in residential settings,[423] it was confirmed as a policy priority in May 2020.

[419] The expression *'environnement ordinaire*' means inclusion of people with disabilities in all sectors and activities.
[420] *Accompagnants des élèves en situation de handicap* – AESH.
[421] *Diplôme d'etat d'accompagnement éducatif et social* – DEAES). https://ecole-et-handicap.fr/laccompagnement-des-eleves-en-situation-de-handicap-2-dispositifs-daccompagnement/avs-et-aesh-vers-la-professionnalisation/
[422] *Unité localisée pour l'inclusion scolaire* – ULIS. https://eduscol.education.fr/cid53163/les-unites-localisees-pour-l-inclusion-scolaire-ulis.html
[423] The current COVID-19 pandemic has had a dramatic impact on the older population. In April 2020, more than 25,000 people in EHPADs had been infected by COVID-19 and more than 8000 deaths had been registered. The mortality rate due

It is also worth noting the special attention paid to **family care-givers** in 2019.

- The Act of 22 May 2019 was designed to facilitate carers taking leave and securing carers' rights.
- The approval in October 2019 of an allowance for recipients of carer's leave, which is aimed at encouraging carers to make use of the leave that was in little use up to that point.[424]
- A national strategy to encourage support for carers (see Box 1).

In addition, there was a specific measure designed to **improve care quality, along with access and affordability**: the Act of 24 July 2019 on transforming the health system, establishing the integration of existing co-ordination measures into complex pathways (MAIA, PTA, PAERPA, networks) within a unique support measure (DAC).

The ASV Act (implemented in January 2016) is the latest general reform to date. Although criticised for the insufficient financial resources attached to it,[425] it has led to steps forward, as follows.

Concerning **access and affordability**, it is worth mentioning measures to scale-up the APA and reduce the number of people subject to co-payment. The ASV Act has thus led to a 6.5 % increase in APA expenditure (Libault, 2019). It also highlighted prevention and co-ordination, with the introduction of a special body – the funders' conference to prevent older people's loss of autonomy – to manage co-ordination at the level of *départements*.

Concerning **informal care**, the ASV Act has had a real impact by extending the legal definition of those (spouse, partner, cohabitee, relative) who can be a family care-giver: it can now also be someone residing with, or having close and stable ties with, the person concerned. To facilitate the work of care-givers, the law recognises the 'right to respite', which provides the means for a care-giver to take a break. Care-giver leave (*congé de proche aidant*) is designed for those caring for an infirm relative or a relative coping with a loss of autonomy. Care-givers can ask their employer to temporarily interrupt their professional activity, while keeping their position and rights in the company. This leave can last up to three months (except if there is a collective agreement) and can be renewed. It became payable from 30 September 2020 (opening up pension rights): EUR 52 per day for a single person, and EUR 43 for people living in a couple. New legislation adopted in May 2019 to promote the recognition of care-giving was designed to secure the social rights of care-givers by: standardising the position across different social security schemes; putting in place a system or relay with social or medico-social services; issuing a care-giver's card for identification purposes (especially by health professionals); and developing a care-giver's guide and web-

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to COVID-19 is closely linked to age and gender. 50 % of patients with COVID-19 admitted into intensive care were aged 65 or over and 60 % of them were men.

[424] Sirven, N., Naiditch, M., and Fontaine, R., *Etre Aidant et Travailler: Premiers résultats d'une enquête pilote* [Combining care-giving and working: first results of a pilot survey], Université Paris-Descartes, 2015. https://www.agevillage.com/media/library/pdfs/Rapport_enquete_MACIF_0810.pdf.

[425] Le Bihan, B., 'France Anticipates Ageing Society through New Piece of Legislation', *ESPN Flash report* 2016/18, European Social Policy Network (ESPN), European Commission, Brussels, 2016.

based information/guidance. Information can also be found in special centres for older people and their carers (*maisons des aînés et des aidants*).

Furthermore, familial solidarity leave (*congé de solidarité familiale*) is open to *'every employee whose ascendant, descendant, brother, sister, or person sharing the same home, suffers from a life-threatening pathology or is at an advanced or terminal stage of a serious and incurable affection'*. It allows the employee to suspend their professional activity to care for someone losing autonomy, for a period of three months (renewable). It cannot be deferred or refused by employers. During this time, the care-giver can benefit from the daily home support allowance,[426] paid by the social security system.

Concerning **quality**, the ASV Act extended CPOM to all social care facilities.

***Box 1: Planned reforms and ongoing legislative process and debates***

***The 2019 Libault report***

*Although maintaining older people in their homes and increasing freedom of choice in the organisation of care are put forward as priorities, the 175 measures presented in the report concern both the development of good-quality support in the home and care in residential settings.*[427] *Concretely, three main strands can be identified, as follows.*

*(a) A series of measures aimed at reorganising the various types of existing financial support, which include: creating a new home-based cash benefit to replace the current APA with three components – personal assistance, technical support, and respite (for carers); and merging healthcare and social care expenditure in residential homes to reduce the remaining amount which is payable by residents.*

*(b) The development of services in the home and in residential care through: renovating residential homes and making them more open to the outside world (a renovation plan worth EUR 3 billion has been announced); increasing the supervision rate in residential homes by 25 %, by recruiting 80,000 employees at an estimated cost of EUR 1.2 billion; creating 60,000 places in residential homes; developing alternatives to residential homes or home-based care (i.e. temporary accommodation and collective housing); and creating indicators to measure the quality of services available in residential homes.*

*(c) Measures designed to increase support to informal carers who provide care to older relatives. This will be done by simplifying procedures and access to information, providing financial aid to support informal carers, and facilitating informal carers' work/life balance.*

*The set of measures announced in the report will require massive public funding, with an estimated additional amount of EUR 9.2 billion by 2030. The report argues in favour of financing LTC policy through national solidarity, by recognising 'loss of autonomy' as a genuine social protection risk and including this in social security funding legislation. The favoured scenario is that an existing pay deduction – the contribution to reducing the social debt (CRDS) – which will have been fully paid by 2024, will be converted into funding for loss of autonomy. Recourse to private funding is presented as additional to public funding. One possibility could be to take account of a share of property assets when calculating the level of the benefit received, in order to support funding of home-based and residential care. Alternative scenarios, such as creating new mandatory pay deductions, or extending*

[426] *Allocation journalière d'accompagnement à domicile*, AJAP.
[427] Le Bihan, B. and Sopadzhiyan, A., 'Future Trends in French LTC Policy: The Libault report', *ESPN Flash Report* 2019/25, European Social Policy Network (ESPN), European Commission, Brussels, 2019.

*working time by cancelling a national holiday, have so far been ruled out. Besides this financing challenge, the governance of LTC policy needs to be clarified, as it involves two main institutional actors – regional health agencies and local councils – which can sometimes have a tense relationship.*[428]

*Two documents were produced in 2019 to confirm the chosen direction: the El Khomri report, which outlines measures and steps for the reorganisation of the LTC workforce; and the national strategy for mobilisation and support to carers, which concerns all carers (whatever the age of the care recipient). Following in the vein of the ASV Act and the Libault Report, it stresses the need to open up new rights for carers and anticipate their exhaustion and isolation, and to diversify and increase the reception capacities of respite places.*

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The announcement of a comprehensive old age and loss of autonomy plan, based on the Libault report, is the next step awaited by all professional and institutional actors. Confirmed as a priority due to the impact of the COVID-19 crisis, it presents key opportunities for addressing LTC challenges in relation with demographic changes, as follows.

- The recognition of 'loss of autonomy' as giving rise to a genuine right to social protection, with its inclusion in social security funding legislation and the confirmation of the EUR 9.2 billion extra public spending by 2030.
- The reorganisation of the LTC homecare workforce with a reform of the complex pricing system; and an improvement in working conditions for care workers to make the sector more attractive.
- The recruitment of qualified and recognised healthcare and social care professionals in residential settings.
- Further development of co-ordination efforts in order to simplify the existing schemes, avoid fragmentation or overlapping measures, and facilitate continuity of care for older people.
- Building on what has already been done in terms of compensation, conciliation or supportive measures for informal carers, the development of policy measures to support informal care combined with the improvement of services at home and in residential settings in order to enlarge choice for informal carers.

  The law of 7 August 2020 on social debt and autonomy creates a fifth area of the national health service, dedicated to responding to the loss of autonomy of older people and people with disabilities, with a EUR 1 billion funding project. It is the first step in a global reform of the French system.

[428] Le Bihan, B. and Sopadzhiyan, A., 'The development of integration in the elderly care sector: a qualitative analysis of national policies and local initiatives in France and Sweden', *Ageing and Society*, Vol. 39 Issue 5, 2019, pp. 1022-1049. doi:10.1017/S0144686X17001350.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 64.0 | 67.0 | 68.7 | 70.0 |
| Old-age dependency ratio, 2019 | | 25.2 | 32.5 | 40.0 | 49.3 |
| Population 65+ (in millions), 2019 | Total | 10.5 | 13.5 | 16.4 | 19.4 |
| | Women | 6.2 | 7.7 | 9.2 | 10.9 |
| | Men | 4.3 | 5.8 | 7.2 | 8.5 |
| Share of 65+ in population (%), 2019 | | 16.4 | 20.1 | 23.9 | 27.7 |
| Share of 75+ in population (%), 2019 | | 8.5 | 9.4 | 12.5 | 16.6 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 21.3* | 22 | | |
| | Women | 23.4* | 23.9 | 24.9 | 26.5 |
| | Men | 18.9* | 19.8 | 20.9 | 22.6 |
| Healthy life years at the age of 65, 2018 | Total | 9.4* | 10.8 | | |
| | Women | 9.8* | 11.3 | | |
| | Men | 9* | 10.2 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 6,184.8 | 6,856.2 | 7,853.2 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 3,268.2 | 3,974.5 | 5,188.3 |
| | Women | | 2,030.3 | 2,408.8 | 3,171.4 |
| | Men | | 1,237.9 | 1,565.8 | 2,016.9 |
| Share of potential dependants in total population (%), 2019 | | | 9.2 | 10.0 | 11.2 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 24.0 | 24.0 | 26.7 |
| Share of population 65+ in need of LTC** (%), 2019* | | 24.9 | 21.5 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 4.9 | 4.6 | 6.1 |
| Share of population 65+ receiving care at home (%), 2019 | | | 6.2 | 6.2 | 7.4 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 46.0 | 45.0 | 50.5 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 45.2 | 38.7 | | |
| | Women | 46.2 | 42.0 | | |
| | Men | 42.7 | 31.9 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 21.4 | 15.1 | | |
| | Women | 24.2 | 17.2 | | |
| | Men | 17.9 | 12.4 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 16.4 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 3.6 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 968.4 | 981.5 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 1.7 | 2.3 | | |
| | % Women | | 91.2 | | |
| Share of population providing informal care (%), 2016 | Total | | 14.1 | | |
| | Women | | 16.3 | | |
| | Men | | 11.9 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 10.5 | | |
| | Women | | 11.9 | | |
| | Men | | 8.5 | | |

**data not available for all Member States; In terms of French national data, the Libault report estimated that in 2018 about 830,000 FTE staff work with dependent older people (6.3 LTC workers per 100 people aged 65 or more).*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 2.0 | 1.9 | 2.1 | 2.6 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 2.0 | 1.9 | 2.3 | 3.7 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 61.9 | 69.6 | 70.7 | 71.4 |
| Public spending on home care as % of total LTC public spending, 2019 | 28.4 | 24.8 | 24.8 | 26.0 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 9.7 | 5.6 | 4.5 | 2.6 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 1.3 | 1.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.6 | 0.6 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.4 | 0.4 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.1 | 0.1 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# CROATIA

***Highlights***

- Croatia is going to be faced with a large projected drop in population by 2050, and the ageing of the population is the most striking socio-demographic trend. Ageing of the population in the circumstances of recent intensive emigration of young working-age groups means that older people are increasingly being left alone without a direct family support.
- The long-term care (LTC) system is fragmented and is one of the least developed parts of the healthcare and social care system in Croatia. The governance structure of LTC, with separate services in the hands of the state, is part of a political clientelist structure that is poorly co-ordinated with other private and civil society stakeholders.
- There is a need to build the capacities of stakeholders in the social care system to make reliable assessments of needs for LTC services. The prices for accommodation in private homes are double those in public homes of the same standards. The quality of services is a real challenge for private residential care providers and for de-institutionalisation (e.g. expansion of family homes with a relatively lower level of quality standards). There are no viable reforms currently being undertaken in this complex sector with increased demand.
- Public support for the provision of care for older people is not sufficient. Care for dependent older members has been left to the family and the local community, which often do not have an adequate expert support or financial aid from the state.
- There are pronounced regional inequalities in the coverage of the older population by residential and home- or community-based services. Croatia is witnessing workforce shortages in LTC because wages are significantly lower than those in more developed countries, and due to high emigration to other EU-27 Member States in recent years.

# 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

## 1.1 Demographic trends

The EU Ageing Report included Croatia in a group of Member States with the highest projected drop in population by 2050.[429] In 2019 the population was 4.1 million; the projection for 2030 is 3.8 million, and 3.4 million for 2050. The population aged over 65 is

[429] European Commission, *The 2018 Ageing Report: Economic and budgetary projections for the 28 EU Member States (2016-2070),* Brussels, 2018. Available at https://bit.ly/2KAqG8r. See also: European Commission, *The 2018 Ageing Report: Underlying assumptions and projection methodologies*, Brussels, 2017. https://ec.europa.eu/info/sites/info/files/economy-finance/ip065_en.pdf.

currently 0.8 million (men 0.3, women 0.5); the projection for 2030 is 1.0 million (men 0.4, women 0.6), and for 2050 is 1.1 million (men 0.5, women 0.6). The ageing of the population is therefore the most striking socio-demographic trend.[430]

The old-age-dependency ratio in 2008 was 26.7 % and 31.6 % in 2019; the projection is 40.6 % for 2030, and 52.5 % for 2050. The share of population aged 65 and over in 2008 was 17.8 % and is currently 20.6 %; the projection for 2030 is 25.1 %, and for 2050 it is 30.2 %. The share of population aged 75 and over in 2008 was 7.3 % and is currently 9.4 %; the projection for 2030 is 11.8 %, and for 2050 16.5 %. Life expectancy at age 65 in 2008 was 16.7 years (men 14.7, women 18.2), and is currently 17.9 (men 15.9, women 19.5). Healthy life years expectancy at age 65 in 2008 were 6.5 (men 6.6, women 6.5), and are currently 5.0 (men 5.0, women 5.0).

The share of the population aged 65 and over in need of LTC, defined as having at least one severe difficulty in personal care and/or household activities, increased from 29.7 % in 2014 to 38.5 % in 2019. The number of potential dependants aged 65 and over in 2019 was 239,600, while the projection for 2030 is 272,000, and for 2050 300,300. The share of potential dependants in the total population was 9.7 % in 2019, with a projection of 10.7 % for 2030 and 12.1 % for 2050. On this evidence, meeting the needs of older people and providing LTC will be a pressing challenge.

Ageing of the population in the circumstances of recent intensive emigration of young working-age groups means that older people are increasingly being left alone without direct family support. Such developments will have a long-lasting impact on the availability of resources to meet the needs of older population. Negative demographic trends are more visible in rural areas and in the less developed regions. The estimated share and number of potential dependants in the total population is relevant evidence on which to base systematic analyses, public debates, and policy development in this field.

## 1.2 Governance and financial arrangements

The LTC system is fragmented and is one of the least developed parts of the healthcare and social care system in Croatia. In addition, the term LTC is not officially used as a concept. Although most services and benefits are administered through the social care system,[431] some services and rights are provided by other systems with little co-ordination between them. Resources for LTC are generated through tax-based systems. The Ministry of Demography, Family, Youth and Social Policy (MDFYSP) is in charge of benefits and services provided through the social care system, while the Ministry of Croatian Defenders is in charge of the LTC needs of war veterans. The healthcare needs of older people are provided through the healthcare system under the Ministry of Health, which is also in charge of palliative care. Public homes for older people are owned by counties and the state, although standards and rules of financing are set by the MDFYSP. Counties, cities, municipalities, and civil society organisations can finance community care, which is significantly underdeveloped and

[430] All data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.
[431] The main regulatory framework is the Social Care Act, OG (157/2013, 152/2014, 99/2015, 52/2016, 16/2017, 130/2017, 98/2019), along with several decisions made based on it.

fragmented.[432] There is a growing private sector, particularly in residential care for older people and infirm people. This reflects the general shortage of places in public homes for older people, and especially for infirm or frail people in urgent need of healthcare (for example those who are terminally ill or who suffer from various mental illnesses).[433] However, information on care provided in the private sector is very scarce, particularly in relation to fees and quality of services. Private homes and other services they provide are not included in the local governance structure of LTC.

Benefits and services are fragmented and accounted for as parts of the social care, healthcare, and war veterans' systems. The available information suggests that spending by Croatia on LTC is a very small part of GDP, and is among the lowest in the EU, much below the EU-27 average. The projected increase is also the lowest among the EU-27 Member States. LTC is financed from the state budget and from private sources.[434] The government covers the cost of subsidies for all beneficiaries in public homes from the state budget, as well as the full costs for vulnerable groups, as decided by centres for social care (CSCs), in private and public homes. Beneficiaries in public institutions pay subsidised prices, while those in private institutions pay market prices. The financial arrangements of LTC in public homes are not transparent and are marked by political clientelism.[435] Services for beneficiaries are largely subsidised, and the government is not prepared to introduce economic prices for such services. In such circumstances, public homes have a kind of 'monopolistic' position, which means that private providers cannot compete with them.

The social care strategy for older people in Croatia for 2017-2020[436] (SCSOP) addresses the issue of LTC. The annual activities focus more on the quality of services, spread of services in communities, and awareness-raising. Based on the SCSOP, the government recently adopted the Act on National Benefits for Older People, with the intention of helping people older than 65 who do not earn a pension.[437]

The governance structure of LTC is not transparent, and there are no clear procedures and criteria for people seeking a place in a public home, either for themselves or for their family members, as the most affordable type of LTC. The less developed part of the country relies

[432] According to Article 116 of the Social Welfare Act, funds are provided in the state budget for: the right to cash benefits in the social welfare system; the right to social services, except in cases prescribed by this law; financing the work of social welfare centres; and financing the work of social care homes and community service centres founded by the Republic of Croatia. Furthermore, Article 117 stipulates that local and regional government bodies must provide funds for performing social welfare activities in accordance with the law, special regulations, and the plan for social services in their area. Local government bodies, including in the City of Zagreb, may be required to provide funds for heating costs. They also provide funds for the work of social welfare institutions of which they are the founder (including investment costs; property maintenance; equipment; transport; and investment/maintenance relating to IT and other communications equipment). Large cities and cities with county headquarters are obliged to fund the service of food in public kitchens, as well as services in shelters or accommodation for homeless people.

[433] Bađun, M., 'Financiranje domova za starije i nemoćne osobe u Hrvatskoj' [Financing homes for older and infirm people in Croatia], *Revija za Socijalnu Politiku* 24(1), pp. 19-42, 2017.

[434] Bađun, 2017.

[435] Bežovan, G., 'Hrvatska socijalna politika u vremenu globalizacije i europeizacije' [Croatian Social Policy in Time of Globalisation and Europeanisation], in: Bežovan G. (ur./ed.), *Socijalna Politika Hrvatske* [Croatian Social Policy], Zagreb: Pravni Fakultet Sveučilišta u Zagrebu, 2019, pp. 59-108.

[436] *Social Care Strategy for Older People in the Republic of Croatia for the Period 2017-2020*, Government of the Republic of Croatia, 2017.

[437] OG 62/2020.

heavily on informal services provided by families, and in two counties there are still no public homes for older people. Palliative care services do not cover all geographical areas of the country.

## 1.3 Social protection provisions

In terms of cash benefits in the social care system,[438] people aged 66 and over can rely on different social assistance benefits, including the guaranteed-minimum benefit, which is the basic social assistance benefit and is means-tested. In 2018, about 9500 users of the guaranteed-minimum benefit were older than 66. In addition, there is a means-tested housing allowance; an assistance and care allowance; a personal disability allowance; and benefits to cover the personal needs of beneficiaries in homes for older people. For people in need of LTC, the most important ones are those for assistance and care and for personal disability. The assistance and care allowance is granted to someone who cannot cover their basic living needs on their own, as a result of which they have a critical need for help and care from another person, including in: organising meals; preparing and taking meals; procuring groceries; cleaning; dressing and undressing; and personal hygiene.[439] The allowance is administered by the CSCs, and in 2018 there were 27,086 beneficiaries older than 65.[440] The personal disability allowance can be claimed by someone with a severe disability or a serious long-term health condition, in order to cover their basic needs. The CSCs administer the allowance, including carrying out a needs assessment. In 2018, there were 5660 beneficiaries older than 65.[441] Older people in residential homes are entitled to means-tested benefits to cover their personal needs, in cases where the state pays for all or part of the cost of their accommodation.

Obtaining a place in public care homes is not subject to a transparent procedure. As well as income and age criteria, informal connections – such as the recommendation of people with political power – play a significant role. The government pays part of the cost, or even the total cost, depending on the means test. The government should improve the needs assessment for those seeking a place in public homes, in order to give priority to dependent people with the most severe needs.[442]

In addition, home-help services may be provided to older people who, in the assessment of the CSCs, need assistance or care that cannot be provided by a parent, spouse, or children. Access to these services is means-tested. Home-help services can be provided by: social care homes; community service centres; civil society associations; religious communities; other legal entities and craftsmen who provide social services; and anyone who provides social services as a professional activity. In 2018, 9595 old people received these services and 3328

[438] Social Care Act, OG (157/2013, 152/2014, 99/2015, 52/2016, 16/2017, 130/2017).
[439] Article 57 of Social Welfare Act (GG 157/13, 152/14, 99/15, 52/16, 16/17, 130/17, 68/19, 64/20).
[440] See government statistics portal at: https://mdomsp.gov.hr/pristup-informacijama/statisticka-izvjesca-1765/statisticka-izvjesca-za-2018-godinu/10185
[441] Government statistics portal.
[442] For example, in 2018 in public homes owned by counties, there were 1418 users whose main 'need' was 'loneliness', 385 whose main 'need' was 'disturbed family relations', and 508 where it was inappropriate housing conditions in family. 73 % of residents in public homes are there because of disease, infirmity or disability. See government statistics portal.

of them received financial support from the CSCs.[443] Public care homes and civil society organisations provide daycare services for older people, such as occupational therapy with meals. The informal care sector within families is rather large (Bađun, 2017).[444]

The needs assessment for access to care is very much in the initial stage of development, with weak follow-up. According to the SCSOP, it is the responsibility of the MDFYSP. There is a real need to improve the capacity for, and practice of, needs assessment for LTC, and also for other social welfare services.

Related cash and/or in-kind benefits for older care recipients and/or their carers do not exist. The SCSOP addresses this issue.

## 1.4 Supply of services

Residential care is mainly provided through homes for older people, and the number of places available is rising. At the end of 2016, there were three state homes for older people (for 171 users), and 45 county homes (for 10,801 users), making a total capacity of 10,972 in public homes (state and county homes have the same mode of operation). Additionally, there were 112 non-state homes owned by private persons, non-profit organisations, and religious communities (for 7604 users). Other private legal entities, such as companies, had 95 homes (for 1811 users). This means that there was a capacity for 9415 users in non-state settings (accredited and supervised by the MDFYSP). In total, 86 % of residential care places were within public homes. In addition there were 361 family homes, which are smaller residential homes (6-20 places) with prescribed space and staff, and which had capacity for 5549 users. There were also 1544 approved foster families (for 3479 users). In foster families, users are treated like dependent members of family. The conditions for foster care as a form of social accommodation service are determined by the competent social welfare centre. Also, the decision on the permit for foster care is issued by the competent social welfare centre according to the residence of the foster parent. Supervision of foster families is carried out by the Ministry of Labour, Pension System, Family and Social Policy. Beneficiaries (adults who use social services based on the decision of the social welfare centre) are obliged to participate in the payment of the price with his income. The state subsidies services for vulnerable users. The total capacity of all these providers, state and non-state, was for 29,414 people, or 3.7 % of those aged over 6 (Government of the Republic of Croatia, 2017). Non-state homes offer residential care and are accredited and supervised by the MDFYSP.

There is a great need for palliative care; this has only recently started to develop, more as a part of the healthcare system than as a part of LTC.[445]

In total, there are about 6300 people employed in homes for older people. Executive staff from public homes are very often part of a local political clientelist structure, with questionable management skills. In private sector there is more need for qualified

[443] Government statistics portal
[444] 17 % of people aged 35-47 have to care for family members. This negatively affects the participation of women in the labour market.
[445] *National Programme for the Development of Palliative Care in the Republic of Croatia 2017-2020*, Government of the Republic of Croatia – Ministry of Health, 2017.

professionals with managerial skills. There is anecdotal evidence of understaffed private homes.

There is no evidence on the size of the informal and undeclared care workforce. Traditionally, informal care has played an important role inside families. Nowadays there is an increasing amount of undeclared care, whereby well-off families employ someone (often on a good salary) to care for a family member.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Care for older people in Croatia is mostly provided by families or relatives in the informal sector. According to MDFYSP statistics, less than 3 % of the population over age 65 (about 23,000 out of 838,000) are cared for outside the family in organised forms of **residential care,** such as public and private homes for older people, or in **community care** such as family homes and foster care families. Most public homes are decentralised and operate under the auspices of county authorities. One of the main challenges in LTC in Croatia is a growing demand for affordable residential care, which exceeds supply, especially in public institutions. Supply is more responsive to demand in the private sector, but at much higher prices, **which reduces the affordability of LTC for many older people** with low pensions and generally few family resources[446].

The following figures illustrate the low responsiveness of the public sector. According to the MDFYSP, the capacity of the 48 public homes for older people increased by only 426 places during 2004-2014. The number of private homes increased from 48 to 94 during 2004-2018, and their capacity by 2552 places, to 6623. The fundamental difference between public and private homes for older people is in the price, which is generally twice as high in private homes as in public ones. There were 10,917 people in public residential homes in 2018, in private residential homes there were about 5700; in the homes of other legal entities engaged in the care of older people there were about 1240 older people, and around 5500 people were in family homes.

From the perspective of the beneficiaries (older people), the best option is to obtain accommodation in a public home, which is much cheaper than in private residential homes. Prices in public homes are EUR 400-600 monthly (HRK 2500-4000) (Babić, 2018), whereas in private homes they are EUR 800-1200. Some older people choose a somewhat cheaper family home, which also offers a lower standard of comfort and fewer social services than residential homes. It is important to emphasise here that the government continuously implements a kind of cost-savings approach within the social care system, and one obvious result is insufficient capacity in LTC system, which in turn **seriously endangers the affordability and accessibility of LTC services**.

[446] Babić Z., 'Decentralizacija socijalne skrbi i socijalne nejednakosti: slučaj Hrvatske' [Decentralisation of social welfare and social inequality: the case of Croatia], Revija za Socijalnu Politiku [Croatian Journal of Social Policy], 25(1), pp. 25-47, 2018, https://doi.org/10.3935/rsp.v25i1.1458

In addition to the underlying problem of insufficient capacity, the *issue of inequalities in access* to social services for older people is becoming more pronounced. These inequalities appear in the way that some beneficiaries succeed in finding accommodation in public homes for which there are very long waiting lists and for which the access criteria are not transparent (placements are decided by the commission in each home, with wide discretionary powers). A second group of older people is those unable to find a place in a public home, and therefore 'forced' to pay for a place in a more expensive private home. A third group is those 'in between': not able to pay for private accommodation, but not so dependent as to be given a place in a public home by their CSC: they have to rely on their own resources, or sometimes on their relatives and local solidarity networks, because community- and home-based care is underdeveloped. Research also shows the issue of significant inter-county inequalities in the availability of services for older people. For instance, in Bjelovar-Bilogora, Zagreb, Požega-Slavonia, and Varaždin counties, and in the city of Zagreb, the existing accommodation capacities in LTC cover 3.5-4.1 % of the population aged over 65; whereas in Krapina-Zagorje and Virovitica-Podravina counties, which probably have somewhat lower demand for residential care accommodation, capacities are significantly lower and cover only 1.3 % of the population over 65.[447]

In the last 10 years, a greater focus has been on homecare services. The government therefore launched the 'wish for – women's employment programme' in 2017 using EU funding.[448] The programme was intended to support the employment of disadvantaged women, focusing on women older than 50, to provide support and care for older and disadvantaged people in their communities. In 2018, this programme was serving 24,429 people (Government of the Republic of Croatia, 2017).

Although public social protection systems have a positive impact on reducing the risk of poverty among older people, the risk of poverty is still higher for older people with LTC needs than for the older population in general. In Croatia, an older person earning a low income has to devote over half their income to pay for care, leaving less than half of their already low income to cover basic living expenses.[449]

Benefit entitlement and support options are rather complex and the CSCs provide counselling on how to understand them.

## 2.2 Quality

The LTC quality framework in Croatia is implemented under the by-law on the standard of quality of social services, based on the Social Care Act[450] and has been in force since 2014. Quality standards have become mandatory for all providers of residential and non-residential

[447] Babić Z., 'Decentralizacija socijalne skrbi i socijalne nejednakosti: slučaj Hrvatske' [Decentralisation of social welfare and social inequality: the case of Croatia], *Revija za Socijalnu Politiku* [Croatian Journal of Social Policy], 25(1), pp. 25-47, 2018. https://doi.org/10.3935/rsp.v25i1.1458.
[448] https://www.mrms.hr/zazeli-program-zaposljavanja-zena-financiran-iz-europskog-socijalnog-fonda
[449] OECD, *Measuring Social Protection for Long-term Care in Old Age: Final Report,* Organization for Economic Co-operation and Development (OECD), 2019.
[450] *Zakon o Socijalnoj Skrbi*, NN 157/2013. Available at https://narodne-novine.nn.hr/clanci/sluzbeni/2013_12_157_3289.html.

social services, private and public ones, except for foster families. An important aspect of the implementation of these standards is the training provided by the MDFYSP. Providers then have to produce the following three reports: (a) a report on the first self-assessment of compliance with the quality standards of social services, within three months of completing training; (b) a progress report on implementing quality standards, within 12 months of completing training; and (c) a quality standards compliance report, developed within 24 months of completing training.

The Healthcare Quality Act regulates the qualitative framework for LTC in health services. The Ministry of Health publishes a by-law on healthcare quality standards covering issues such as: the procedure for granting, renewing, and cancelling the accreditation of healthcare providers; and a plan and programme for implementing healthcare quality assurance, improvement, promotion, and monitoring. Healthcare institutions with more than 40 employees are obliged to establish a special unit for ensuring and improving the quality of healthcare; and other healthcare institutions, companies, and private healthcare professionals who provide healthcare are obliged to designate someone who is responsible for the quality of service.

In practice, certain defined quality standards should be respected in the process of establishing homes for older people and the infirm. Founders have to submit a request to the MDFYSP for a decision that a home is in accordance with the Institutions Act (OG 76/1993, 29/1997, 47/1999 and 35/2008) and the Social Care Act.[451] Based on that decision, the founder registers a home as a public institution of social protection in the court. Thereafter, the founder submits a request to the county office for social policy (COSP) for a declaration that the home meets all the prescribed conditions regarding the professional staff employed, space and facilities, and quality standards. The request has to be submitted no later than two months before the scheduled start of operation. The COSP issues a final decision based on a finding of a professional committee, which checks that all requirements for providing services are compliant with the ordinance on minimum conditions for the provision of social services (OG, 40/2014).

The procedure for establishing family homes for older people (up to the maximum of 20 people) is somewhat easier and decentralised to the COSP which, in this case, issues a final decision/permit for work. Due to heavy demand and an easier and cheaper procedure for founding them, family homes for older people have seen a big expansion in last 10 years. However, they have a lower level of quality standards than other homes for older people, and there is insufficient quality control by the institutions in charge. After a sad accident at the beginning of 2020 in which six old people died in this type of family home, the MDFYSP announced that the criteria for establishing them will be stricter under the new Social Care Act, and that more people will be employed in the inspectorate department for monitoring –

[451] According to Article 184 of the Social Welfare Act, eligibility for the provision of social services is examined by a commission appointed by the minister responsible for social welfare. However, in the case of the provision of services to older people and people with disabilities, homeless people, home-help services and services provided by natural persons as a professional activity, the procedure is delegated to the regions and the city of Zagreb. The same applies to the licensing of care providers under Article 185.

there has been a serious lack of inspectors and other staff employed in the MDFYSP and COSP for monitoring quality standards.[452/453]

## 2.3 Employment (workforce and informal carers)

According to data published by the MDFYSP, in 2018 there were 6332 workers employed in all residential homes for older people (4025 in public and 2307 in private homes), which was 0.5 % of total employment and around 0.2 % of the total workforce in 2018. 88 % of LTC workers were women, while the EU-27 average was 90.8 %. In public homes, around 46 % of workers are professional carers (around 20 % are professional health workers such as nurses and other healthcare personnel, and 26 % are care workers). In private homes for older people, the structure of employees is similar, with a somewhat higher share of professional care workers at 57 %, (31 % of workers are professional healthcare workers such as nurses and therapists, and 26 % are professional carers). Data regarding age or educational structure are not available.

According to Eurostat and OECD data,[454] Croatia is among the EU-27 Member States with a very low number of formally employed workers in the LTC sector.[455] The number of LTC workers employed per 100 people aged over 65 in 2016 was 1.7 in Croatia, whereas the EU-27 average was 3.8. However, the OECD data points to an increase compared with 2011, when there was 1.0 worker per 100 people aged over 65: this was mostly due to the expansion in the private sector. According to the 2016 Eurostat data (see Section 5, Table 5.4), the share of the total population providing informal care in Croatia was 6.4 % (7.4 % of women, 5.2 % of men) compared with a much higher rate of 10.3 % in the EU. The share of informal carers who provide more than 20 hours of informal care per week was significantly higher in Croatia at 32.9 % (38.6 % of women and 23.7 % of men) compared with the EU-27 average of 22.2 % (24.6 % of women and 18.5 % of men).

There are shortages of professional staff in the LTC sector, due to high emigration to more developed countries in recent years, especially by nurses but also care-givers.[456] Some private homes for older people have therefore employed migrants and asylum-seekers;[457/458] but the problem could become even greater in the future, because some EU-27 Member States (e.g. Austria) have this year ended a seven-year transitional period of restrictions on free movement of labour from Croatia. Regarding educational and training qualifications, in Croatia personal care workers in the LTC sector should complete six months of formal training (OECD, 2020), while nurses in LTC should obtain a high school degree. Due to the positive economic growth in the last several years, wages in the LTC sector in Croatia are

[452] The home in Andrasevac, where six old people died, later turned out to have never been monitored or visited by inspectors.
[453] https://www.euronews.com/2020/01/11/six-people-dead-after-fire-engulfed-part-of-nursing-home-in-croatia
[454] OECD, 'Who Cares? Attracting and retaining care workers for the elderly', *OECD Health Policy Studies,* OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en
[455] See Section 5 'Background Statistics'
[456] https://www.jutarnji.hr/vijesti/hrvatska/udruge-medicinskih-sestara-traze-konkretne-mjere-odlazak-kadrova-u-inozemstvo-dovodi-u-pitanje-osiguranje-izvrsnosti-u-skrbi-za-pacijente/9932770
[457] https://www.tportal.hr/vijesti/clanak/traze-i-azilante-za-rad-u-starackom-domu-20190924
[458] People under international protection are employed in exceptional cases; an asylum-seeker may be employed whose status has not been resolved in accordance with the Law on International and Temporary Protection.

improving. Nevertheless, wages are still significantly below those in more developed EU-27 and neighbouring countries, such as Austria and Italy, where many care workers have found placements in recent years; this could become a serious obstacle to the sustainability of the LTC sector in the medium and long run.

### 2.4 Financial sustainability

According to the 2021 Ageing Report[459] projections (see Section 5, Table 5.5), Croatia spent 0.4 % of GDP on LTC in 2019, which was lower than the EU-27 average (1.7 % of GDP). Regarding the structure of LTC costs, Croatia spent almost half of the LTC budget on cash benefits in 2019, 47.0 % was allocated to residential care, and only 3.0 % to homecare. In 2019, the EU-27 devoted on average 48.1 % of LTC spending to residential care, 25.5 % to homecare, and 26.4 % to cash benefits. It should be noted that Croatia spends much more on cash benefits, and much less on homecare, than the average of other Member States.

Future projections in the 2021 Ageing Report (reference scenario) suggest that spending on LTC in Croatia is expected to increase slightly from the current 0.4 % of GDP to 0.5 % in 2030 and further to 0.6 % in 2050. In a risk scenario (where a 'convergence effect' means that as countries become richer, they are likely to spend a larger proportion of their GDP on LTC), it is expected to increase to 0.6 % of GDP in 2030, and then more rapidly to 1.3 % in 2050. At the same time, the EU-27 average is expected to be 2.5 % of GDP in 2050 in the base scenario and 3.4 % in the risk scenario (see Section 5, Table 5.5). This means that Croatia would significantly lag behind the EU-27 average investment in the LTC sector until 2050.

### 2.5 Country-specific challenges regarding LTC for other age groups in need of care

As has been noted, although population ageing is the most striking socio-demographic trend which will influence LTC demand for older people in the future, there are other risk groups in Croatia such as children, and people with disabilities. For people with disabilities who need LTC, a process deinstitutionalisation is under way by moving them out of residential settings and into flats (but the problem is a lack of financial resources, because these are more expensive). Another challenge may be ensuring continued funding of some independent living projects, for small groups of people with disabilities, started by non-profit organisations.

## 3 REFORM OBJECTIVES AND TRENDS

In the period 2017-2020 there have been no significant reforms related to LTC. Three key strategic documents have addressed LTC in this period: the SCSOP, the national programme of palliative care development (NPPCD), and the national strategy of equal opportunities for people with disabilities (NSEOPD).

[459] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

The SCSOP points to a shortage of LTC services (residential or non-residential). According to the MDFYSP data, 6348 applications for accommodation in residential homes for older people were turned down in 2018 due to under capacity. In 2018, only 2.1 % of older people in Croatia were placed in residential homes. The most important objectives set by the SCSOP during 2017-2020 were as follows: (a) reform the method of service payment in public residential homes in such a way that it is equal for all users in public and private homes; (b) improve and intensify the monitoring and inspection of service-providers for older people; (c) extend care-giver status to those who care for older people who have an increased need for LTC services; (d) equalise the development of residential and community-based services on the entire territory of Croatia; (e) increase the level of service quality in residential homes; (f) improve the education, training, and competences of the employees who work with older people; and (g) keep older people informed about their rights, and raise public awareness about older people's rights.

None of the above-mentioned objectives has been achieved, nor have there been major developments in their implementation. The position remains that: older people in public homes enjoy a privileged status compared with those in private homes (because of lower costs; see Section 2.1); the surveillance of service-providers is inadequate, because the number of inspectors is very low (10 for the whole of Croatia);[460] care-giver status is reserved for people who care for children with developmental difficulties or for people with disabilities; there is unequal access to care services, especially in certain parts of Croatia; older people are poorly informed about their rights;[461] and there are no incentives in terms of education or higher wages for employees who work with older people.

The NSEOPD has very modest objectives regarding LTC for people with disabilities. It emphasises that it is important to: develop housing for people with disabilities with the most severe physical impairments; to ensure orthopaedic aids, treatment, and rehabilitation for Homeland War veterans with the most severe disabilities; and to develop specialised palliative care.

The NPPCD is a follow-up to the strategic plan for palliative care development for 2014-2016, where an initial assessment of the need for palliative care was made. The main proposals in the NPPCD are limited to: the assessments of needs and resources; the regulation of the system for providing palliative care; organisation of the network of palliative care; capacity enhancement; and the development of palliative care for vulnerable groups (e.g. children, veterans, and older people). So far, some slight progress has been made: one or more co-ordinators and one or more mobile teams for palliative care have been established in each

[460] The MDFYSP states that 218 inspections were carried out in 2019, out of which 164 referred to different providers of accommodation for older and infirm people. Irregularities were identified in 130 cases out of 164. Inspectors issued prohibition orders for 25 residential or family homes and other penalties for 105 homes. In addition, 34 indictment proposals were submitted (mainly because of an excessive number of beneficiaries or undeclared work). See: https://www.index.hr/vijesti/clanak/svaki-inspektor-samo-jednom-mjesecno-ide-u-nadzor-nekog-starackog-doma/2148861.aspx?index_ref=read_more_d.

[461] For example, one study has shown that less than a quarter of older people knew the difference between the contract of maintenance for life (a provider acquires the right to all or part of the real estate of a care recipient at the time of their death) and the contract of maintenance until death (a provider acquires the right to all or part of the real estate of a care recipient at the time the contract is drafted). The media has frequently reported on the abuse of the contract of maintenance until death.

county, there are at least some forms of palliative care in each county, and education about palliative care at the college level has been developed. The NPPCD stated that all counties should devise their own palliative care strategies by 2018.

It can be stated that LTC has been poorly developed and researched, there are no relevant data, and there is no clear vision for the development of LTC in the future. Debates about key LTC challenges are occasional (e.g. about the balance between cash benefits and services, financing models, employment of people who provide services, quality standards or the issue of unequal access to services in different parts of Croatia). Research studies in Croatia point to the inadequate role of the government in the provision of care for older people, and indicate that the family itself mainly takes on LTC.[462] Care for dependent older people has been left to their families and the local community, which often do not have adequate expert support or financial aid from the state.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

Addressing the LTC challenges in Croatia implies, first of all, carrying out a comprehensive research project that would gather data about all key aspects of LTC (e.g. current and future needs for LTC of the older population in the regions; the development of residential and non-residential services; funding sources and financing methods; needs and challenges for carers and care recipients; quality indicators; and monitoring), which would be a basis for analysing LTC models fitted for Croatia, and for medium-term and long-term development strategies.

Given that the demand for LTC services significantly exceeds the supply,[463] it is necessary to expand the supply of residential services and to reduce regional inequalities in coverage of the older population by residential services. In addition, it is necessary to expand home- and community-based services, taking account of their regional accessibility and affordability.

The financing model of public homes should be changed, through the introduction of a unique means-tested model of financing in which payment would be based on the services performed (thus, subsidising well-off citizens by the state would be avoided). The prices of services would be market prices (the current prices have not been changed for decades). In addition, a unique priority list for accommodation in public homes should be established (it has not existed so far).

[462] Dobrotić, I. and Laklija, M., 'Obrasci društvenosti i percepcija izvora neformalne socijalne podrške u Hrvatskoj' [Patterns of sociability and perception of informal social support in Croatia], *Društvena Istraživanja* [Social Research], Vol. 21, No 1, pp. 39-58, 2012; Bađun, M., 'Neformalna dugotrajna skrb za starije i nemoćne osobe' [Informal LTC for older and infirm people], *Newsletter* No 100, Institut za Javne Financije, Zagreb, 2015; Strmota, M., 'Stanovništvo 50+ u ulozi pružatelja i primatelja neformalne skrbi u Hrvatskoj' [Population aged 50 and over population in the role of providers and receivers of informal care in Croatia], *Revija za Socijalnu Politiku* [Croatian Journal of Social Policy], Vol. 24, No 1, 2017, pp. 1-18. www.rsp.hr; Štambuk, A., Rusac, S. and Skokandić, L., 'Profil neformalnih njegovatelja starijih osoba u gradu Zagrebu' [The profile of informal care-givers of older people in the city of Zagreb], *Revija za Socijalnu Politiku* [Croatian Journal of Social Policy], Vol. 26, No 2, 2019, pp. 189-206. www.rsp.hr.

[463] *Godišnje Statističko Izvješće o Domovima i Korisnicima Socijalne Skrbi 2018* [Annual Statistical Report on Social Welfare Homes and Beneficiaries in the Republic of Croatia], MDFYSP, 2019. https://mdomsp.gov.hr/pristup-informacijama/statisticka-izvjesca-1765/statisticka-izvjesca-za-2018-godinu/10185.

In particular, it is necessary to improve the monitoring and surveillance of service-providers for older people, through the delegation of inspection authorities to the counties, which are the founders of most social welfare homes for older people.

The right to care-giver status should also be extended to those people who care for older people (so far, this right has been reserved only for those caring for people with disabilities).

It is important to enhance the co-operation between different sectors (social care, healthcare, and the war veterans' system), between different geographical levels (national, regional, and local), and between different stakeholders (public, for-profit, and not-for-profit providers).

There are workforce shortages in LTC because the wages are significantly lower than those in more developed countries, and due to high emigration to other EU-27 Member States in recent years. The first step should be to retain workers by offering higher wages and better chances for professional advancement.

As LTC in Croatia has been predominantly informal, provided primarily by family members and relatives, the balance between work and care should be improved through flexible work, which would allow shorter or longer periods of leave, depending on needs.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 4.3 | 4.1 | 3.8 | 3.4 |
| Old-age dependency ratio, 2019 | | 26.7 | 31.6 | 40.6 | 52.5 |
| Population 65+ (in millions), 2019 | Total | 0.8 | 0.8 | 1.0 | 1.0 |
| | Women | 0.5 | 0.5 | 0.6 | 0.6 |
| | Men | 0.3 | 0.3 | 0.4 | 0.5 |
| Share of 65+ in population (%), 2019 | | 17.8 | 20.6 | 25.1 | 30.2 |
| Share of 75+ in population (%), 2019 | | 7.3 | 9.4 | 11.8 | 16.5 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 16.7* | 17.9 | | |
| | Women | 18.2* | 19.5 | 20.7 | 23.1 |
| | Men | 14.7* | 15.9 | 17.2 | 19.7 |
| Healthy life years at the age of 65, 2018 | Total | 6.5* | 5.0 | | |
| | Women | 6.5* | 5.0 | | |
| | Men | 6.6* | 5.0 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 395.2 | 407.9 | 408.0 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 239.6 | 272.0 | 300.3 |
| | Women | | 151.7 | 167.5 | 179.0 |
| | Men | | 87.9 | 104.6 | 121.4 |
| Share of potential dependants in total population (%), 2019 | | | 9.7 | 10.7 | 12.1 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 28.3 | 28.2 | 29.3 |
| Share of population 65+ in need of LTC** (%), 2019* | | 29.6 | 38.5 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 2.4 | 2.4 | 2.5 |
| Share of population 65+ receiving care at home (%), 2019 | | | 1.2 | 1.2 | 1.2 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 7.5 | 7.5 | 7.7 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 12.5 | 12.6 | 12.6 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 26.4 | 26.6 | 26.4 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 47.6 | 71.0 | | |
| | Women | 46.7 | 75.5 | | |
| | Men | 49.9 | 62.2 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 5.9 | 12.3 | | |
| | Women | 7.3 | 12.3 | | |
| | Men | 3.7 | 12.4 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 34.2 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 11.2 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 224.3 | 227.9 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 1.0 | 1.7 | | |
| | % Women | | 87.4 | | |
| Share of population providing informal care (%), 2016 | Total | | 6.4 | | |
| | Women | | 7.4 | | |
| | Men | | 5.2 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 32.9 | | |
| | Women | | 38.6 | | |
| | Men | | 23.7 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.4 | 0.4 | 0.5 | 0.6 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.4 | 0.4 | 0.6 | 1.3 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 54.7 | 47.0 | 47.3 | 48.3 |
| Public spending on home care as % of total LTC public spending, 2019 | 34.3 | 3.0 | 3.0 | 2.9 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 11.0 | 50.0 | 49.7 | 48.8 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.2 | 0.2 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# ITALY

***Highlights***

- Italy is the EU-27 country with the highest share of people aged 65 and over and 75 and over among the population. But living longer in Italy does not mean necessarily living in better health: healthy life expectancy at age 65 is 9.5 years in Italy, below the EU-27 average level (9.9 years) and lower than most EU-15 Member States. These latter data show that the problem of frail older people is more pronounced than in many other countries.
- Although public expenditure on long-term care (LTC) is not low compared with the EU-27 average, the Italian public LTC system is still strongly based on informal care and migrant care workers, often with irregular contracts, and with a limited diffusion instead of residential and homecare services.
- In homecare and residential care there are no national standards, and many decisions and evaluation criteria are delegated to the regional and municipal level. This situation produces an extreme heterogeneity in evaluation conditions and access criteria.
- The most important LTC scheme in Italy is the companion allowance[464] (CA), which does not require of beneficiaries any type of accountability on how the money granted is spent. More than half of Italian public expenditure on LTC therefore goes to a programme that intrinsically does not include any quality-assurance safeguards.
- The current COVID-19 pandemic has dramatically shown the weaknesses of such a system. For the first time in decades, the attention to LTC in Italy has strongly increased due to the dramatic events related to the pandemic – and more specifically, to the situation (and deaths) in residential care. The number of deaths and the need to shelter the population in the upcoming months from a new upsurge of the pandemic might be a trigger for rethinking the whole public LTC system, which does not need too many added resources but a better way of using them, strengthening services instead of focusing (mainly) on cash transfers.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM

### 1.1 Demographic trends

[464] *Indennità di accompagnamento.*

Italy is a society ageing faster than the rest of the EU. There are currently almost 14 million people living in Italy who are aged 65 and over.[465] They represent 22.8 % of the population, the highest share in the whole EU-27 (where the average is 20.3 %). 11.7 % are aged 75 and over; this is also the highest percentage in the EU, where the average is 9.7 %.

Projections are that by 2050 more than one third of the Italian population will be aged 65 and over (33.7 %). The gap with the EU-27 average will increase, as the same projection is for 'only' 29.5 % in the EU-27. It is also projected that the share of the population aged 75 and over will reach a particularly high share in the future in Italy: it is expected to be 13.8 % by 2030 and then 20.7 % by 2050 (the highest percentage by far in the whole EU-27 in both years).

The increasing gap between Italy and the EU-27 average can be largely explained by a relatively high life expectancy at age 65 (21.4 years – the third highest value after France and Spain, and well above the EU-27 average of 20.2 years), and by a very low fertility rate (projections are that Italy will have 4.5 million fewer inhabitants by 2050).

However, living longer in Italy than in many other countries does not necessarily mean living in better health. Although Italians have a greater life expectancy at 65 than in most EU-27 Member States, they have a lower one in terms of living in good health. Healthy life expectancy at age 65 is 9.5 years in Italy, below the EU-27 average level (9.9 years) and quite a bit lower than most EU-15 Member States (15.7 years in SE, 11.9 in DE, 11.4 in ES, 11.3 in DK and 10.8 in FR). These latter data show that the problem of frail older people is more pronounced in Italy than in many other countries.

Around 5.6 % of the Italian population was potentially dependent in 2019 (the figure is expected increase to 6.2 % by 2030 and 7.5 % by 2050). The share of those aged 65 and over in need of LTC is high (around 28.7 %), reflecting the data on healthy life expectancy above.

These last two data are particularly important in the light of the current COVID-19 pandemic. Epidemiological data seem to show that the virus has particularly deadly outcomes among the frail older population. Central, eastern, and southern Member States (including Italy) have a very high share of frail older among the population aged 65 and over compared with Member States such as the Scandinavian or German-speaking ones.

## 1.2 Governance and financial arrangements

The Italian LTC public system is organised around two main pillars: cash transfers and services. Within the services pillar, a further distinction must be made between healthcare-related LTC provision and social care-related LTC. These pillars follow a different logic and have different governance and financial arrangements. As a result, co-ordinating the whole LTC system is very complicated. The main cash transfers programme, the CA, is a national programme managed by the National Institute for Social Security (INPS); all individuals diagnosed with a severe disability are eligible, without any age- or income-related restriction.

[465] All data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.

It is the only real social right in the Italian public LTC system. It is funded through general taxation.

Whereas the CA is a national programme, services are run by two different subnational tiers of government. Healthcare-related LTC is a regional government responsibility, given that this is the level where the governance of all healthcare provision takes place. Social care-related LTC is a responsibility of local municipalities. There are two main types of homecare provision: support for daily living tasks (cooking, cleaning, etc.) and nursing activities. However, compared with the CA, individuals do not have a similar right to access to LTC services, either in healthcare or in social care. As a matter of fact, regions and municipalities can decide (and vary over time) the economic resources invested in LTC services and the type of services that are privileged (homecare, residential facilities or LTC hospital beds). Moreover, while the CA does not have any type of co-payment and it is tax-exempt (the latter is estimated to cost EUR 2 billion in lost revenues, which should be added to the overall amount of resources transferred), services can be provided with co-payments. The amount and type of user fees also change according to regional and local policy decisions. Admission to services is based on needs but also on income levels: co-payments can be a relevant part. The criteria for access to residential care and homecare are quite differentiated in the country, varying between regions and the municipality of residence, as do the criteria for co-payment.

Public LTC spending was equivalent to 1.7 % of GDP in 2019, equal to the EU-27 average. The CA absorbed more than half of public resources invested into LTC (around 52 % in 2019). In this respect, Italy is among the Member States that devote most of their LTC public spending to cash transfers (the EU-27 average is around 26 %). Italy spent around EUR 13.6 billion on the CA in 2016, covering around 1.83 million beneficiaries. Among these beneficiaries, most were aged 65 and over: 78.1 %.[466] In particular, the INPS spent EUR 10.4 billion in 2016 just on older people. The coverage level of the CA is not low: around 10.8 % of individuals aged 65 and over received it in 2016. The generosity of the CA is more limited, at around EUR 515 per month in 2017, and the programme does not vary the amount according to the level of needs.

Limited resources are invested in homecare: 19.5 % of the total public expenditure in this field in 2019. The equivalent value in the EU-27 is 25.5 %. The level of investment in residential care is also limited: only around 28 % of total LTC public expenditure goes on this type of provision (around 48 % in the EU). Apart from these two main pillars, care leave also plays a role.[467] The Italian care leave system is relatively generous and well developed. It offers a combination of both short-term leave for urgent cases and longer leave provisions (Laws No 104/1992, 388/2000, and 183/2010, as amended subsequently). Care leave, which is fully compensated and pensionable, is only granted for public and private employees who have to care for relatives or children with severe disabilities; it is subject to the principle of the 'sole carer', which means that in any household no more than one worker can attend to the

[466] Data were retrieved at the INPS website (www.inps.it), statistical database (*banche dati statistiche*).
[467] Further information can be found in the *ESPN Thematic Report on work-life balance measures for people of working age with dependent relatives – Italy* (February 2016). The basic rules and regulation of care leave programmes has not changed in recent years.

needs of someone with severe disability. Carers are entitled to two types of leave: three working days of paid leave (at 100 % of the last salary) per month and up to two years of paid leave (at 100 % of the last salary, subject to an annual ceiling – e.g. EUR 48,495.36 in 2019.

## 1.3 Social protection provisions

Anyone diagnosed with a severe disability is eligible for the main cash transfers programme, the CA, without any age- or income-related restriction. At the same time, there are no uniform social rights for LTC service provision in either healthcare or social care: regions and municipalities decide who is entitled, depending on the economic resources they allocate to LTC services.

Needs evaluation is different as between the CA and access to services. For the CA there is a county commission, chaired by representatives of the INPS, and the evaluation of disability is done by different types of professionals (including doctors). For homecare and residential care for people with LTC needs, there are no national standards and many decisions and evaluation criteria are delegated to the regional and municipal level. This situation produces an extreme heterogeneity in evaluation conditions and access criteria.

## 1.4 Supply of services

Whereas a relatively large part of the older population with LTC needs is covered by the main cash transfer programme (around 11 % of people aged 65 and over receive the CA), the coverage rate of services is much lower: 3.2 % of older people can access residential facilities, and 4.7 % homecare. There are very few frail older people who can access LTC services who do not also receive the CA. No reliable data are available on the type of service provision (public, private for-profit, and not-for-profit).

Although data on LTC provision in terms of coverage rates among those aged 65 and over are not available for all EU-27 Member States and all types of provision, Italy lags behind many other EU-27 Member States, especially those in central and northern Europe, both for residential care and homecare. The comparison with Member States such as France, the Netherlands or Finland, for instance, is striking. In addition, the coverage of cash programmes in Italy (the CA) is not particularly high compared with many other countries. Data on the supply of LTC beds confirm this picture: although the number has increased over time (there were 393.3 beds per 100,000 inhabitants in 2014, and 415.8 in 2017), it remains comparatively quite low: among the 23 Member States providing data on this topic, Italy is among the seven Member States with the lowest density (with BG, EL, HR, LV, PL, RO). Scandinavian countries, the Benelux area, and Germany have twice as many beds per inhabitant as Italy, and France and Austria have almost twice as many.

Although the topic is discussed in Section 2 in more detail, it is important to underline that the Italian LTC system can count on around 1.9 million informal workers, 0.8 million migrant care workers (often with irregular labour contracts), and only 260,000 LTC workers.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

As already underlined in the previous section, the comparatively low share of people aged 65 and over benefiting from residential care or homecare could point to potential problems of access to formal LTC services in Italy. The point was also stressed in the country specific recommendation for Italy in 2019.[468]

In order to measure the scale of the problem, it is necessary to estimate the potential demand for LTC services. A first estimate can be based on the share of people aged 65 and over with severe difficulty in activities of daily living (ADLs) or instrumental activities of daily living (IADLs): as reported in Section 1.1, the data relative to Italy show a high share of around 28.7 %. A second estimate can be based on the share of people aged 65 and over who receive the CA, given the fact that this cash transfer is given to all those with a very severe disability, independent of income or other personal characteristics: in 2019 this figure was around 11 % of people aged 65 and over. A third estimate can be obtained by looking at the share of people aged 65 and over declaring the use of homecare services for personal needs: this percentage for Italy was 9.5 % in 2019.

If only 4.7 % of people aged 65 and over receive public homecare, and 9.5 % declare that they use homecare services for personal needs, how can we explain the difference? Of course, part of the explanation might come from the fact that the latter figure comes from a survey where only a sample of individuals aged 65+ is covered (though this is supposed to be representative of all those in the age group). However, a more satisfactory explanation might lie in the large private care market in Italy, often based on irregular labour contracts and migrant work.[469] By comparing these two pieces of data, it seems that only around half of those receiving homecare do so through the public LTC system, whereas the other half rely on private provision.

The fact that public LTC only partially covers social care and healthcare needs in Italy is clearly evident when examining two phenomena: the role of informal carers; and the share of households in need of LTC not using professional homecare services, for either financial or non-availability reasons.

Italy has only a relatively limited number of informal carers (around 5.8 % of the population – in the EU-27 the average is 10.3 %). However, when these people become carers, they are 'trapped', given the fact that they often provide more than 20 hours of care per week (see Section 2.3).

[468] In particular, the recommendation argued that: 'more home and community-based care and long-term care is key to provide support to people with disabilities and other disadvantaged groups' (p. 12), and: 'Investment in long-term care should take into account the wide geographical disparities in the availability of services' (p. 14). These quotes are from: *Recommendation for a COUNCIL RECOMMENDATION on the 2019 National Reform Programme of Italy and delivering a Council opinion on the 2019 Stability Programme of Italy*, No 9936/19 – COM(2019) 512 final, Council of the European Union, Brussels, 2019.

[469] Pasquinelli, S., 'Le badanti in Italia: quante sono, chi sono, cosa fanno' [Family care workers in Italy: how many there are, who they are and what they do], in Pasquinelli, S. and Rusmini, G. (eds), *Badare non Basta*, Ediesse, Roma, 2013, pp. 41-55.

At the same time, a relatively high percentage of households in need of LTC do not use professional homecare services either for financial reasons or because of non-availability (respectively 36.9 % and 30.3 %). For both these indicators, Italy is above the EU-27 average: only slightly in the case of financial reasons (35.7 % in the EU-27), but very significantly for non-availability (9.7 % in the EU-27). In particular, Italy clusters together with most central, eastern, and southern Member States in relation to financial reasons for non-use of professional homecare services, whereas it is 25 % or lower in most continental and northern Member States (AT, BE, DE, FI, FR, IE, SE). In relation to the availability of professional care services, Italy has the highest share in the EU-27 of households declaring a lack of services.

Unfortunately, data are not available on access and affordability in relation to residential care. Practically all services are based on co-payments and, given the fact that the coverage rate is relatively low, waiting lists are common, although there are no official data on the size of the phenomenon.

## 2.2 Quality

There is no overall definition of LTC quality in Italy either at national or regional/local level. Moreover, there is no definition of quality of care in either the healthcare or the social service sector.[470]

Looking at the governance of the LTC system (including quality assurance), in Italy the national government is responsible for quality control at system level, but it shares responsibility with the regions. The latter adopt slightly different solutions and, more importantly, have been able to implement quality-assurance measures, to varying degrees. In particular, southern Italian regions on average had, and still have, more problems than central and northern Italian ones in drafting and implementing quality-assurance practices.

The most important LTC scheme in Italy is the CA, which does not require of beneficiaries any type of accountability as to how the money granted is spent. In other terms, more than half of the Italian public expenditure on LTC goes to a programme that intrinsically does not include any quality-assurance safeguards.

Italy did not perform particularly well in the past in relation to LTC quality assurance. In a comparative study done a decade ago,[471] the strengths of the Italian model were mostly concentrated in its accreditation system, whereas it recorded low scores for most other facets (legislation, national standards/guidelines, quality management systems, audits, etc.). As the present report shows, the situation has only partially improved.

There is no LTC quality framework available either in healthcare or in social services. Moreover, there is not even an established debate around the issue.

[470] Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V. and Schulmann, K., *From Disability Rights towards a Rights-based Approach to Long-term Care in Europe: Building an index of rights-based policies for older people*, European Centre for Social Welfare Policy and Research, Vienna, 2019.
[471] Interlinks, *Quality Management and Quality Assurance in Long- Term Care: European overview paper*, European Centre for Social Welfare Policy and Research, Vienna, 2010.

Given the absence of a quality framework, LTC quality is assured through the following tools: authorisation and accreditation (related to organising services and spaces – e.g. square meters for each beneficiary in residential care, the type of equipment each room should have); the ratio between beneficiaries and different kinds of professional staff (e.g. nurses, doctors, care assistants); legislation addressing abuses and mistreatment of LTC recipients; and professional requirements for workers employed in the sector (certificates of specific skills and education levels). The use of these tools varies according to whether the services are residential/home-based, or alternatively whether they are related to healthcare or social care.

Informal care should be supervised by case managers and social workers as part of their tasks supporting individuals with LTC needs and their families. However, given the limited presence of social workers and case managers compared with the number of individuals with LTC needs, the quality assurance on informal care that can be provided is limited.

## 2.3 Employment (workforce and informal carers)

Italy has a relatively low number of LTC workers. This is not surprising if the limited development of LTC public services and the use of irregular care workers are taken into consideration.

There were around 260,000 LTC workers in Italy in 2016, mostly women (83.5 %), equal to 1.9 per 100 people aged 65 and over. This ratio has increased over time: it was 1.4 in 2011. However, it remains much lower than in the EU-27 as a whole (3.8 in 2016), and in particular is much lower than in northern and continental Member States (e.g. 12.4 in SE, 8.1 in DK, 8.0 in NL, 5.1 in DE). In this respect Italy is closer to many central and eastern Member States, plus Portugal and Greece, than the rest of the EU.

However, the data just presented refer mostly to regular occupations in LTC, whereas an Italian characteristic is the overwhelming presence in the care labour market of (irregular) migrants:[472] a stable estimate over time is that there are around 800,000 such workers. Given the fact that most workers are employed by households – in many cases with irregular contracts (in terms of working hours declared, working schedules, etc.) – labour conditions in the sector are often not particularly good.

The high incidence of (irregular) migrant care workers is related to several factors: the limited coverage of residential care; the presence of a homecare system with a medium-to-low level of coverage; and the relatively extensive access to a cash benefit (the CA), which is not means-tested and does not require accountability on how it is spent. As a result, such a system is not able to sustain LTC needs, and in particular the needs of low-income households, in terms of the affordability, accessibility, and quality of services. The level of the monthly CA (around EUR 515) means that it is only enough for recipients to employ a migrant care worker if household incomes are adequate: it is not enough for low-income households. The result is that informal care (when present and available) is the main source of LTC for low-

[472] Pavolini, E., Ranci, C. and Lamura, G., 'Long-term care policies in Italy', in Greve, B. (ed.), *Long-term Care: Challenges and perspective*, Farnham, Ashgate, 2016.

income households with frail older people, given the difficulty of access to formal public services (especially residential ones).[473]

Italy has only a limited proportion (5.8 %) of the population who are informal carers, compared with other EU Member States; but once people become carers, they are 'trapped' in this type of activity, given the fact that 41 % of them provide more than 20 hours of care per week. This places Italy in a group of southern Member States such as Greece and Spain, as well as Ireland and several central and eastern Member States (e.g. BG, PL).

No real support measures for informal carers (such as training/up-skilling, skills validation, and respite) are available at the national level. There are local and regional experiments but they are limited.

## 2.4 Financial sustainability

Financial sustainability issues are not a priority for the Italian public LTC system, given the relatively contained level of expenditure on LTC and the fact that projections show limited expenditure growth over the next 10 years, even under the AWG 'risk' scenario of the 2021 Ageing Report.[474] Moreover, the problem seems in Italy more related to GDP growth than to LTC expenditure growth, given the very low pace of growth of the Italian economy in the last decade. The situation could be more problematic by 2050, but would still be in line with general EU-27 trends, especially under the AWG risk scenario.

More than financial sustainability in itself, what seems important is to improve the efficiency and efficacy of LTC public expenditure. Reforms in this policy field should be aimed at redistributing more resources: the possible introduction of some sort of income criteria in relation to access to, and the generosity of, the CA should be taken into consideration. Such a choice seems to be necessary, and it could allow part of the resources currently spent on higher-income beneficiaries to be redistributed to lower-income beneficiaries or to strengthen home and residential services.

A first set of challenges comes with the functioning and regulation of the CA. More than half of public economic resources on LTC are spent on this cash programme. The role of the CA within the LTC system for older people in Italy has even increased over time: in 2019 the CA absorbed around 52.3 % of public resources invested in LTC. The absence of accountability requirements on beneficiaries leads frequently to a use of this transfer in an irregular way in the private care labour market (Pavolini et al., 2016). A second problem is that CA benefits are flat-rate: there is no differentiation according to how severe the disability is.

In overall terms, a more robust system of homecare services and residential care would be required to match the needs of the frailest. Otherwise, the Italian LTC system risks becoming more and more unequal in terms of access to formal (public and private) care, especially considering that the share of very old people (aged 80 and over) among those with LTC needs is increasing. The traditional approach − based on public cash allowances combined with a

[473] Barbabella, F., Poli, A., Di Rosa, M. and Lamura, G., 'L'assistenza domiciliare: una comparazione con altri paesi europei', in *I Luoghi di Cura*, No 3, 2019.
[474] EU Economic Policy Committee Working Group on Ageing Populations and Sustainability (AWG).

reliance on both within-household informal care and migrant care (often working in a grey market) – is showing its shortcomings, and social inequalities are becoming increasingly important and problematic. In particular, social inequalities take two forms: class/income inequality, and territorial inequality.

A study comparing the Italian LTC system with those in three other Member States (DE, DK, FR),[475] showed that care systems based on services grant higher access to formal care, and exhibit lower inequalities, than those based more on cash transfers. Moreover, Member States where cash-for-care programmes and family responsibilities play a bigger role suffer from inequalities in access to formal care. Because its system is based more on cash allowances (the CA) than services, Italy shows the highest level of inequalities among frail older individuals in accessing formal care, out of the four countries in the study. Frail older Italians have problems of access to LTC services not only in relation to income/class, but also in relation to where they live. The coverage rate of residential and homecare services in southern Italy is half or less of that in central and northern Italy. The coverage in central and northern Italy is closer to the average in west European Member States, whereas in southern Italy it is extremely low (Pavolini et al., 2016).

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

LTC needs for young people and adults with severe disabilities have been addressed in several ways in Italy, including: policies targeting inclusion in the education system and labour market; services supporting their social and health needs; and cash transfers – the CA is also provided to young people and adults with disabilities. The system of public intervention is relatively developed.

However, there is an area of needs that will require further public attention in the future. Most young people and adults with severe disability live at home, with parents and relatives. The expanding life expectancy of these people has started to create in the last decade a new need, in relation to the type of care that should be provided when their informal carers (parents or relatives) start to age and will not be able to attend to and help them as before. The term used in the Italian debate to refer to this type of problem is: '*dopo di noi*' ('what will happen after us' – where the 'us' refers to parents and other informal carers). This problem will probably affect many more individuals and households in the future. In recent years, the Italian parliament has passed laws in support of informal carers and of solutions designed to cope with the '*dopo di noi*' issue. Nevertheless, the topic will require further innovation in terms of solutions and investments.

[475] Albertini, M. and Pavolini, E., 'Unequal inequalities: the stratification of access to formal care among the elderly Europeans', *Journals of Gerontology*, Social Science, 1-10, 2016.

# 3 REFORM OBJECTIVES AND TRENDS

No major LTC reforms have been introduced, planned or even discussed in detail in recent years in Italy. In this respect, Italy remains one of the few EU-27 Member States, at least looking at those belonging to the 'old' EU-15, where no innovation has taken place in the last two decades in this policy field.[476]

Things might change in the near future, and it would be desirable if they did. The trigger for changes in the LTC domain could be the current pandemic (see next section on this topic).

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The current COVID-19 pandemic has dramatically exposed the strengths, but also the several weaknesses, of the Italian public LTC system. Italy has so far been one of the Member States most severely hit by the pandemic. In particular, four facets of the pandemic in Italy are tightly connected to the way the Italian public LTC system works, as follows.

- The mean age of patients who have died because of COVID-19 infection has so far been 79 (median 80); in particular, around 53 % of those who have died were 80 and over (31 % were 70-79, around 11 % were 60-69, and around 5 % were under 60). Most of the (older) patients who have died presented several co-morbidities diagnosed before COVID-19 infection (the mean number of previous diseases was 3.3, mostly chronic ones); only 3.6 % of patients who died had no co-morbidities, and only 14.4 % had just one; more than half of all those dying lived in Lombardy (56.9 %).[477] These data show that older individuals with (chronic) needs for LTC have so far been the main victims of the pandemic.
- There seems to be a very problematic situation in residential homes for older people, with a high diffusion of the virus among the residents; ISS, the most important public body in this respect, has carried out a survey of all residential facilities (and specifically nursing homes) in order to understand how many patients have been affected by the virus and died. The survey is still ongoing, but the first results show so far that around 8 % of all residents in nursing homes have died since 1 February 2020. Not all those who have died had the COVID-19 infection, but around 40 % did or at least presented potential symptoms. This means that the COVID-19 mortality rate has probably so far been 3.3 %. Lombardy unfortunately stands out, because its mortality rate is 6.7 %. Among the residential facilities that have answered the questionnaire so far, around 82 % declared that they do not have adequate material to protect workers and patients (gloves, masks, etc.); around 47 % declared that they do not have enough access to tests to diagnose COVID-19 infection; and 34 % declare shortages of personnel.[478] These data show that

[476] Ranci, C. and Pavolini, E., 'Not all that glitters is gold: long-term care reforms in the last two decades in Europe', in *Journal of European Social Policy*, 25(3), 2015, pp. 270-285.
[477] *Characteristics of Covid-19 Patients Dying in Italy: Report based on available data on April 16th, 2020,* Istituto Superiore Sanità (ISS) [National Institute for Public Health], 2020. https://www.epicentro.iss.it/en/coronavirus/bollettino/Report-COVID-2019_16_april_2020.pdf.
[478] *Survey Nazionale sul Contagio COVID-19 nelle Strutture Residenziali e Sociosanitarie: Terzo report* [National survey on the pandemic contagion in residential facilities: third update], ISS, 2020. https://www.epicentro.iss.it/coronavirus/pdf/sars-cov-2-survey-rsa-rapporto-3.pdf.

residential care for (frail) older people is severely under stress and that the shortage of facilities and professional human resources (see Section 2) is becoming a major limitation on the way the Italian public healthcare system (not just the LTC one) can cope with the pandemic – even in those regions, such as Lombardy, where the residential system was more developed (around 20 % of all nursing homes in Italy are located in this region).

- If residential care has never been a strength of the Italian LTC system, homecare 'the Italian way' through informal support (relatives) and migrant care workers has been the main traditional answer, supported through the cash allowance system (the CA). However, the pandemic has exposed the limitations of this type of approach. Relatives and migrant (often irregular) care workers have more problems in providing support in such a critical situation as the current one, where there is an increasing and dramatic need for professional skills in not only social care but also healthcare. Frail older people are the most likely victims of the pandemic, but also the most likely agents of spreading it (among many of those who have died of COVID-19 below the age of 60, there are social care and healthcare professionals working to contain the pandemic).
- In a situation where residential care and the traditional informal solution for homecare seem to show all their limits for coping with LTC needs, an important part of the answer could come from professional territorial services (starting with a strong involvement of general practitioners) and professional homecare services. If the former are actively present in most Italian regions, the latter are scarce, as shown in Section 2. In other terms, in order to develop a more general and effective answer to LTC needs – but also one more suited to the pandemic contingency – Italy would need to have stronger and more integrated territorial and homecare services, organised around professionals, helping frail people at home and supporting their families. In this respect, there is an interesting debate on the reasons why, among the regions of northern Italy most badly hit by the pandemic, Lombardy seems to be the worst off. Among many potential explanations, although all of them are premature given the scarcity of detailed information we have so far, several experts point at the fact that Lombardy has, compared with Veneto and Emilia-Romagna, a weaker co-ordination between its hospital system, residential care, and territorial and home services. A general point on this specific issue was made in a newspaper interview with the former President of the ISS and current member of the World Health Organization.[479] Similar points are also made in a recent study.[480]

For probably the first time in decades, the attention given to LTC in Italy has greatly increased due to the dramatic events related to the pandemic – but also, more specifically, to the situation (and deaths) happening in residential care. The traditional mass media, as well as social media, are full of news, reports, and debates about residential homes and frail older people being left in isolation. Most of this discussion is not framed exactly in terms of LTC, but it is heading in that direction.

[479] 'Siamo ancora nel pieno dell'epidemia, riaprire adesso provocherebbe un disastro' [We are still in the middle of the pandemic, opening now could provoke a disaster], *Repubblica*, interview with Prof. Ricciardi released on 16 April 2020. https://rep.repubblica.it/pwa/intervista/2020/04/10/news/walter_ricciardi_coronavirus_lockdown-253609949.

[480] Arlotti, M. and Ranci, C., *Un'emergenza nell'emergenza: Cosa è accaduto alle case di riposo* [An emergency within the emergency: What has happened in our residential homes], Politecnico di Milano, 2020. http://www.lps.polimi.it/?p=3454.

The number of deaths, and the need to shelter the population in the upcoming months from a new upsurge of the pandemic, might trigger a rethink of the whole public LTC system. As argued in Section 2.4, the system does not need much in the way of added resources, but rather a better way of using them, strengthening services instead of focusing (mainly) on cash transfers.

This situation could represent an opportunity to invest in more residential and homecare services, making it easier to access them. Considering its structural characteristics (a cash-based LTC system that has not developed enough services) and the 'stress test' represented by the recent pandemic, the Italian LTC system needs reforms if it is to cope with rising social demand in the coming decades. The following policy recommendations seem relevant in order to boost opportunities for addressing LTC challenges in Italy:

- widening coverage and affordability in relation to formal LTC services, both residential and at home, in order to ensure that large segments of the population do not have to rely either on informal care or on a grey market made up of migrant care workers, often with irregular labour contracts;
- fostering a better policy on service quality and evaluation;
- revising the way in which LTC public resources are spent on cash benefits, and also the accountability for how beneficiaries use these resources;
- tackling more effectively social and territorial inequalities in access to LTC services.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 58.7 | 60.4 | 59.9 | 58.1 |
| Old-age dependency ratio, 2019 | | 30.7 | 35.7 | 43.9 | 61.5 |
| Population 65+ (in millions), 2019 | Total | 11.9 | 13.8 | 16.2 | 19.6 |
| | Women | 6.9 | 7.8 | 9.0 | 10.8 |
| | Men | 5.0 | 6.0 | 7.2 | 8.8 |
| Share of 65+ in population (%), 2019 | | 20.2 | 22.8 | 27.0 | 33.7 |
| Share of 75+ in population (%), 2019 | | 9.7 | 11.7 | 13.8 | 20.7 |
| Life expectancy at the age of 65 (in years), 2019 | Total | -* | 21.4 | | |
| | Women | -* | 22.9 | 23.8 | 25.6 |
| | Men | -* | 19.7 | 20.5 | 22.3 |
| Healthy life years at the age of 65, 2018 | Total | -* | 9.5 | | |
| | Women | -* | 9.2 | | |
| | Men | -* | 9.8 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 3,394.9 | 3,717.2 | 4,359.9 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 2,254.0 | 2,619.4 | 3,469.7 |
| | Women | | 1,460.8 | 1,655.7 | 2,183.1 |
| | Men | | 793.2 | 963.7 | 1,286.6 |
| Share of potential dependants in total population (%), 2019 | | | 5.6 | 6.2 | 7.5 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 16.3 | 16.0 | 17.7 |
| Share of population 65+ in need of LTC** (%), 2019* | | 30.8 | 28.7 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 3.2 | 3.1 | 3.7 |
| Share of population 65+ receiving care at home (%), 2019 | | | 4.7 | 4.7 | 5.5 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 10.9 | 10.8 | 12.7 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 48.4 | 48.7 | 52.0 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 67.3 | 67.5 | 71.6 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 49.6 | 44.2 | | |
| | Women | 51.5 | 44.9 | | |
| | Men | 44.9 | 42.3 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 10.6 | 9.5 | | |
| | Women | 13.1 | 12.0 | | |
| | Men | 7.4 | 6.4 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 36.9 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 30.3 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 393.3 | 415.8 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 1.4 | 1.9 | | |
| | % Women | | 83.5 | | |
| Share of population providing informal care (%), 2016 | Total | | 5.8 | | |
| | Women | | 7.1 | | |
| | Men | | 4.5 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 40.5 | | |
| | Women | | 42.8 | | |
| | Men | | 36.6 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.8 | 1.7 | 1.9 | 2.6 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.8 | 1.7 | 2.0 | 3.1 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 23.7 | 28.2 | 27.4 | 26.7 |
| Public spending on home care as % of total LTC public spending, 2019 | 28.8 | 19.5 | 20.3 | 22.2 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 47.5 | 52.3 | 52.3 | 51.1 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.7 | 0.7 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.2 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# CYPRUS

*Highlights*

- Cyprus displays all the characteristics of an ageing western society with increasing needs, particularly with respect to dependency ratios. A significant increase in the number of dependent people is expected in the next decades.
- Cyprus lacks a comprehensive long-term care (LTC) scheme of universal coverage and does not appear to be keeping pace with the modern approaches of proactive and preventive policies.
- LTC expenditure, as a percentage of GDP, is among the lowest in the EU-27 Member States, resulting in high out-of-pocket (OOP) payments.
- Only a small number of those in need of LTC receive it under formal arrangements, which implies low coverage and/or inadequacy and a very high care burden on informal carers.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

As in most western societies, Cyprus displays the characteristics of an ageing society. As for health status, recent projections on life expectancy and healthy life years lie close to the EU-27 average levels. Cypriots enjoy a high life expectancy, and healthy life expectancy, at birth; but they have a relatively low healthy life expectancy at age 65.[481]

In 2019, the total population on the island was 0.9 million. The share of people aged 65 and over in the total population is projected to rise from 16.1 % in 2019 to 19.5 % by 2030 and 22.3 % by 2050; while that of people aged 75 and over will rise from 6.8 % to 9.5 % and 12.2 % respectively (see Section 5). In addition, an upward trend is observed in the old-age-dependency ratio in Cyprus, from 23.8 % in 2019 to 30.1 % in 2030 and 35.3 % in 2050, signalling a growing demand for LTC services for people aged over 65. This projection should act as a warning of the pressures the Cypriot LTC system may face in the coming decades. In addition, the numbers of potentially dependent people are forecast to grow from 62,100 in 2019 to 76,800 in 2030 and 94,200 in 2050 (see Section 5).

### 1.2 Governance and financial arrangements

Cyprus lacks a comprehensive LTC scheme of universal coverage, though some positive steps have been taken towards it in recent years. LTC expenditure as a percentage of GDP in

[481] All data used in the text come from Section 5 'Background Statistics'.

Cyprus is among the lowest in the EU, resulting in high OOP payments. The total LTC expenditure for 2019 accounted for only 0.3 % of GDP, which was far below the EU-27 average of 1.7 %.

In particular, the LTC system outlined below needs to be further developed, both in the range of benefits provided and in terms of coverage. There is also a need for a better balance between formal and informal care, in favour of the first. A recent positive development regarding LTC in Cyprus is the inclusion of homecare in the new healthcare system of universal coverage, scheduled for full operation in June 2020 (see Section 3). In addition, the forthcoming adoption of two bills to regulate residential and residential care is also expected to support efforts to improve LTC services (see Section 3).

The current LTC system is divided into two distinct parts, one under the responsibility of the Ministry of Health (MoH) and the other under the responsibility of the Ministry of Labour, Welfare and Social Insurance (MLWSI). The MoH is responsible for the provision of all healthcare services, including LTC, while the MLWSI is responsible for the governance of the social protection system and the administration of most cash and in-kind benefits. The regulation and supervision of LTC is the responsibility of the Social Welfare Services (SWS) department of the MLWSI. This responsibility includes monitoring and evaluating the quality of services provided by homecarers and other professionals, as well as the co-ordination of relevant initiatives taken by local communities. Furthermore, the Department for Social Inclusion of People with Disabilities (DSIPD), which falls under the responsibility of the MLWSI, provides a wide array of disability benefits, targeting older people with disabilities, among others.

Both long-term healthcare and social care are financed by general taxation. Public spending on LTC, as a percentage of GDP, is among the lowest in the EU-27 Member States, resulting in high private spending. Private spending mainly consists of direct OOP payments and, to a much lesser extent, on private insurance schemes. Although the share of OOP payments in total LTC expenditure is unclear, it may be similar to the OOP spending on healthcare services, which is 45 %, the highest in the EU-27 in 2017.[482]

The guaranteed minimum income (GMI) – and, in general, the social benefits decree of 2014 – incorporates the scheme for subsidising care services, which covers the social care needs of GMI recipients and their family members. The scheme mainly covers cash benefits and, in justified cases, in-kind services. The SWS also subsidises social care programmes provided by non-governmental organisations (NGOs) and local authorities (state aid scheme under Regulation 360/2012 for the provision of services of general economic interest).

## 1.3 Social protection provisions

[482] OECD/European Observatory on Health Systems and Policies, *Cyprus: Country Health Profile 2019, State of Health in the EU*, OECD Publishing, Paris/European Observatory on Health Systems and Policies, Brussels, 2019. https://www.oecd-ilibrary.org/docserver/2078ba2a-en.pdf.

LTC services are highly means-tested and are provided mainly to people with a high level of dependency (often older people) and those with chronic diseases and physical/learning/mental disabilities.

Only recipients of the GMI may be entitled to subsidised LTC services, with the exception of people with severe disability (motor/paraplegia/quadriplegia/blindness), who are entitled to a subsidy regardless of their income. No qualifying period is defined for LTC eligibility. The SWS collect information on the care needs of the claimant through house visits and specific evaluation/assessment protocols.[483] Additional certificates/reports, including medical reports, may be sought from other services. The information collected is assessed by specialised assessment teams of the SWS. When someone is approved for care provision, a care plan is developed with the co-operation of the beneficiary and the responsible officers. In those cases where the beneficiary prefers a different type of care from the one proposed, they have the right to make their own arrangements. Nevertheless, the level of subsidy will correspond to the approved amount.

In addition to the GMI, older people with disabilities may be entitled to disability benefits. Disability is assessed and certified by a disability assessment centre (DAC). The DAC is a relatively new development and represents the point of reference for disability in Cyprus. It falls under the responsibility of the DSIPD. The assessment of disability is carried out by teams of specialised clinicians, a comprehensive assessment report is prepared, and a disability card is issued. Disability cardholders may be entitled to a broad range of benefits depending on their situation.[484]

The social protection system places more emphasis on cash benefits[485] to those in need of care than on in-kind benefits. However, carers, and in general families with dependent members, may benefit from various services (e.g. house cleaning, basic training for tracheostomy care, and psycho-education).[486] With regards to carers, the LTC subsidy in the form of cash benefits to carers is yet again highly targeted, only covering families of LTC recipients that conform to the strict income and asset criteria of the GMI scheme. The case mix of formal and informal care is unclear, and as such it is not certain that the balance would shift towards formal care at the expense of informal care if there were an attempt to increase in-kind services. At present, there is very limited capacity and infrastructure in the public sector to sustain the demand that would be created by such an initiative. It is also worth mentioning that informal care provided by live-in domestic helpers is currently widespread, and seems to be meeting care needs and at the same time all the other needs, tasks, and chores associated with the daily running of the household.

[483] When SWS officers make home visits they follow a specific evaluation/assessment protocol made up of three main competency themes: self-care, household tasks, and mental state.
[484] For example, among other benefits, there is a care allowance for people who are quadriplegic, and a special allowance for blind people. See: http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/index_en/index_en.
[485] With a few exceptions, such as the employment of a domestic helper, there is still no formal mechanism in place to monitor the spending of these benefits.
[486] Community nurses and mental health community nurses, in-kind benefits given by the DSIPD, and homecare provided by SWS professionals in some special situations.

Families with LTC responsibilities may be eligible for several benefits depending on their needs. As with most LTC-related benefits, these benefits are given in the context of the GMI scheme[487] with the completion of a supplementary application describing the need involved. No other explicit eligibility criteria are in place and each application is assessed on an individual basis. Furthermore, a wide array of non-means-tested disability benefits[488] are given to people with disabilities, which can help improve both the quality of their own lives and the lives of their families.

Women who have stayed out of the labour market, for various reasons including caring responsibilities of the type analysed in this report, may be entitled to a 'social pension'. The social pension is aimed at providing a retirement income to older people residing in Cyprus[489] who – for whatever reason – are not entitled to any other pension. Most of the beneficiaries of this scheme are women who have been excluded from the labour market because of their care responsibilities (including, of course, childcare) and therefore have not accumulated the minimum social contributions required to qualify for a pension.

Lastly, cash benefits are used by recipients to partly cover the salary of domestic helpers (informal carers)[490] and other care expenses, or to make up for income lost as a result of absence from the labour market. These cash benefits mostly apply to those domestic helpers who are salaried live-in employees, and to a much lesser extent to relatives of LTC recipients who function as informal carers and consequently are forced to abandon full-time employment.

## 1.4 Supply of services

LTC services are provided by different bodies, both public and private, but also by voluntary entities, NGOs, and local authorities, among which there is insufficient co-ordination and co-operation. In urban areas, care at home[491] is mostly provided by informal carers (relatives and migrant domestic helpers), and residential care by private residential and daycare service-providers. In the case of the rural areas[492] there is a similar trend; but there is greater participation and support by local authorities, councils, and local charities, which provide subsidised or free services for the residents of their local communities.

Services by local authorities, voluntary bodies, NGOs, and the private sector (for-profit entities) are provided in a variety of settings, including geriatric clinics, homes for older people, hospice centres, state homes, and daycare clinics. Equally, the family has an important and substantial role in LTC provision, and care is often provided by close relatives. As a result, the role of informal care is substantial, with care services provided by spouses/partners, other members of the household, relatives or neighbours − often substituting for inadequate

[487] GMI- basic terms and conditions (in Greek)
[488] DSIPD website http://www.mlsi.gov.cy/mlsi/dsid/dsid.nsf/index_en/index_en?OpenDocument
[489] Applicants should have resided legally in Cyprus for at least 20 years from the date on which they reached age 40, or have resided legally in Cyprus for at least 35 years from the date they reached age 18.
[490] Their services are a substitute for those provided by family members rather than those offered by qualified LTC professionals.
[491] Not to be confused with homecare. In this case it is informal care provided mostly by migrant domestic helpers, and could be considered as undeclared work.
[492] Mainly in large villages, remote communities, and small townships.

state provision. In many cases, care for frail older people (along with other housework duties) is provided by live-in domestic helpers,[493] usually women from Sri Lanka, the Philippines, and Vietnam.[494]

There are no precise national data on the utilisation of the above-mentioned services. The available data show that 7.1 % of people aged over 65 had used homecare services for their personal needs in the previous 12 months in 2019. In 2016, 45.6 % of households in need of LTC did not use formal homecare services due to financial reasons, but only 0.6 % due to service unavailability. Cyprus appears to cover LTC needs mostly by cash benefits (57.1 % of the LTC public spending in 2019) with 37.1 % going to homecare and 5.7 % to residential care services. There are no further data concerning access and utilisation in relation to LTC services. The lack of a comprehensive LTC scheme is hindering the collection of such necessary data. However, the integration of LTC social benefits within the GMI scheme could help in extracting information on the type and the nature of LTC services used in the near future.

The formal workforce participating in the provision of LTC in the public sector is well qualified, and its terms and conditions of employment can be described as satisfactory. However, this is not always the case for the private sector, which is still unregulated. Recently, new private residential and homecare providers have emerged; however, it is not known whether they employ adequately qualified formal carers. The level of pay and the working conditions in the private LTC sector are not as favourable as in the public sector. In 2016, there were 1.3 LTC workers per 100 people aged 65 and over (this roughly translates to around 1300 LTC workers). The profession is clearly dominated by women workers, who account for 90.2 % of those workers providing LTC to people aged over 65. In addition, the share of the population providing some type of informal care was5.2 % in 2016. There are no readily available data on the size of the workforce in both formal and informal care.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Access and adequacy in relation to LTC services are major challenges for any social care system. These challenges are even greater and pressing for Cyprus, since the current system is incomplete, fragmented, and poor in terms of infrastructure and technology, with limited co-ordination and regulation, resulting in very low scores on patient access and coverage in comparison with most other EU-27 Member States. Formal services are provided to only a small part of the population, highlighting the dominant role of informal care. Data from 2016 regarding access by people aged over 65 to formal homecare services, show that the two main

[493] For the purposes of this report, domestic helpers are included in the category of informal carers, even though they provide paid services to the households. The reason for including them in the informal care sector is that their services are more similar to the type of informal care provided by family members, and less so to services provided by qualified LTC professionals.

[494] Kantaris, M., Theodorou, M., Galanis, P., and Kaitelidou, D., 'Access and utilisation of health services by domestic helpers in Cyprus', *International Journal of Health Planning and Management*, Vol. 29, No 4, 2014, pp. 383-393.

reasons hindering access were the high cost (35.7 %) and limited availability (9.7 %) of homecare services.

The absence of a comprehensive LTC scheme further exacerbates the present situation of multiple disparities in coverage, with older people and people with disabilities being two groups negatively affected. Moreover, the absence of rehabilitation services and co-ordinated palliative care create conditions for high OOP payments, thus damaging the affordability of these services.

Amidst this problematic situation, two more factors must also be considered; population ageing, and the consequent rise in the old-age-dependency ratio (see Section 1). Despite the unfavourable situation, this issue receives low priority in government planning and among healthcare policy-makers.[495] It seems that solidarity and mutual support between family members, which still exists largely in Cyprus, together with the low-cost solution of third-country domestic helpers, act as release valves for the current system. It is mainly due to these two factors that informal care for older people is a major part of LTC in Cyprus, which, in conjunction with the inadequacy of public sector provision, greatly slows rate of uptake of formal care.

## 2.2 Quality

Although quality of LTC services is not explicitly described and defined in any law or regulation, it can be traced or derived from relevant policy documents such as the social protection and social integration strategy of 2006 and 2008, produced by the SWS. In some laws and regulations, as mentioned below, there are references to procedures, qualifications, and prerequisites designed to ensure the quality of LTC services, but there is no definition of quality.

At present there is no quality framework that applies to all LTC services. There is also no relevant legislation in place to regulate quality standards for all LTC services. However, there is legislation regarding the quality of services in some areas of LTC, such as residential care and daycare centres. In the field of homecare, a new law is being introduced (see Section 3), the product of many years of discussions and consultations, which will regulate the field for the first time. This law will establish a specific framework for homecare providers, by regulating the provision of services, and by defining minimum quality standards as well as the qualification requirements of carers.

Today, any person or legal entity wishing to become a homecare provider simply needs to apply to the SWS, and in addition meet some basic qualifications such as: a certificate of attendance at an approved care-giver programme; a clean criminal record; a minimum of B1-level proficiency in Greek; a first-aid training certificate; and a certificate of registration with the relevant profession.

Homecare provision is monitored via visits made by social services officers, who are required to follow a specific evaluation/assessment protocol, made up of three competency themes:

[495] Koutsampelas, C., 'Aspects of elderly poverty in Cyprus', *Cyprus Economic Policy Review,* 6(1), 2012, pp. 69-89.

self-care, household tasks, and mental state. Despite the evaluation protocols, there are no formal procedures and mechanisms in place to ensure that the 'quality process' is effectively and systematically monitored, and that measures are taken where necessary to improve quality.

With regards to homecare provided by the nursing services of the MoH, and despite the lack of relevant legislation, there are written procedures that must be followed for quality control, and clinical guidelines which apply to community nursing care provision. There are also audit committees in place for each district, co-ordinating activities and monitoring LTC provision. Incentives to providers or choice for consumers are not relevant to the Cypriot LTC system, for the time being.

Regarding LTC in residential care and daycare centres, quality is monitored by reference to the minimum standards set out in the respective legislation and through regular inspections of the centres. Residential and daycare providers, either public or private sector, must meet certain minimum quality standards such as: the suitability and qualifications of employees; the ratio of employees to beneficiaries; the suitability and condition of facilities; the bedroom area ratio and shared areas ratio for each beneficiary; hygiene facilities; buildings safety and physical access; the suitability and range of LTC services provided; and the provision of socialisation and entertainment activities.

Monitoring of legal minimum quality standards is the responsibility of the SWS, which has set up specialised inspection units in each of the five administrative districts of the country, performing regular inspections and investigating complaints. If minimum quality standards have been met, the SWS issues a certificate of registration[496] for the care-provider. A key area in which monitoring and quality assurance constitute a major challenge is that of the qualifications and registration of professional carers (formal carers). This is also set to change under the new legislation regulating home and community care.

Even though migrant informal carers from third countries have become an important part of informal care provision, there are no predefined criteria for their employment, and, in most cases, they come to Cyprus with a work permit as a domestic helper.

## 2.3 Employment (workforce and informal carers)

The lack of a statutory comprehensive scheme has given rise to a large informal sector where LTC services are provided by families and friends – mainly spouses and children – based on the traditional community values that characterise the Cyprus society and, in particular, the close ties between family members. However, slowly but steadily, the provision of informal care by family members is expected to decline, as people have fewer children and family ties are weakened by geographical dispersion.

[496] This certificate of registration is subject to renewal on a yearly basis.

The availability and the capacity of informal carers to provide care should be an issue of concern. According to a study in 2012,[497] at that time Cyprus had one of the biggest shares of LTC needs provision in the EU-27. More recent data show a significant share of informal carers providing care for more than 20 hours per week. By 2050 it is projected that the number of people aged 20-64 (potential informal carers) will fall, whereas the number of people aged 65 and over (potential dependants) will increase, thus posing a threat to the availability of potential informal carers.

Women are often the primary informal care-givers. In 2016, 14.3 % of women in part-time jobs stated that they were looking after children or incapacitated adults. Moreover, the percentage of women aged 20-64 who were inactive for the same reason was 19.2 % in 2016 (18.6 % in EU-27). Despite this, women's employment rate in Cyprus is close to the EU-27 average (64.1 % vs. 64.3 % in 2015). This may be attributed to the high incidence of informal care provided by live-in domestic helpers.[498]

With regards to MoH nurses providing homecare, one of the department's top priorities is human resources issues such as qualifications and continuing professional development. All such community nurses should hold a postgraduate degree in community nursing and care. The nursing services department is also responsible for quality control of services.

Regarding services provided in residential care and daycare centres, the legislation requires carers to be at least high school graduates, while in certain cases where the residents have specific needs (people with disabilities, HIV+, victims of violence etc.), it requires a further qualification in the form of at least three years of experience relevant to these specific needs.

Although the issue of informal carers' education and training has long been recognised as a priority, appropriate and targeted training programmes are only provided on an ad hoc basis, and at the discretion of community nurses or SWS officers. Routine one-on-one training of informal carers is provided by nurses, social workers, and other healthcare and social care professionals during home visits, covering basic caring skills (personal care and hygiene, and specific medical care). Data collected for informal carers in Cyprus in 2017 as part of the i-Care project[499] revealed a number of learning priorities for informal carers such as: personal care and hygiene; prevention of bed sores and pressure ulcers; basic physiotherapy exercises; managing stressful situations; patient grief reactions; and communication and internet-search skills. Cyprus does not have care-specific leave schemes and flexible time arrangements (respite care) for informal carers. Nevertheless, informal carers of GMI recipients can apply for respite care funding through the 'care services subsidy scheme' of the SWS.

The MLWSI, in an attempt to alleviate the high dependency on informal care, has recently been providing subsidies for the employment of 100 trained full-time carers, to provide specialised support services to people with severe motor disabilities. The implementation of

[497] Lipsyc, B., Sail, E. and Xavier, A., 'Long-term Care: Need, use and expenditure in the EU-27', *Economic Papers 469/2012*, European Commission, 2012. https://ec.europa.eu/economy_finance/publications/economic_paper/2012/pdf/ecp469_en.pdf.
[498] Pashardes, P. and Koutsampelas, C., *Work-life Balance for Persons of Working Age with Dependent Relatives,* European Social Policy Network, (ESPN), European Commission, Brussels, 2016.
[499] Co-funded by EU Erasmus+ programme. Details at: http://www.i-care-project.eu.

this programme began on 1 November 2017 with the aim of subsidising the Cyprus Paraplegics Organisation to employ the carers for a period of 24 months.

Since 2007, there has also been a liaison and advisory service between community nursing services and the Nicosia general hospital; among other things the service provides counselling, guidance, and education to family carers on healthcare issues and on promoting the autonomy and independence of patients. Finally, the Cyprus Red Cross has been organising a series of educational programmes which, among other things, provide training in psycho-social support, first aid, and ethics. The programme commenced in September 2018 with funding by the Norwegian Red Cross, and six training cycles per year are scheduled.

## 2.4 Financial sustainability

Public LTC spending as a share of GDP is forecast to increase in the coming decades from 0.3 % (in 2019) to 0.4 % in 2030 and 0.5 % in 2050 according to the AWG reference scenario of the 2021 Ageing Report[500], and 0.6 % in 2030 and 1.2 % in 2050 according to the AWG risk scenario.[501] However, it will still be one of the lowest in the EU-27 and potentially inadequate to meet the future challenges.

There are no estimates of current and future OOP payments for LTC services, and no clear information with respect to their distribution by type of service or the way in which different population groups are affected by them. The funding mechanisms and budget preparation for LTC are still underdeveloped and there are insufficient data to assess financial sustainability. It is expected that full implementation of the new healthcare system, with the inclusion of homecare as a formal LTC service (see Section 3), will mean that LTC expenditure on formal care will increase. However, this is uncertain since in addition to coverage it depends on several other factors such as accessibility, availability, and quality.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

The current LTC scheme leads to many disparities concerning coverage, adequacy, and access to services, especially for people with disabilities. Furthermore, the lack of a rehabilitation policy (physiotherapy, speech therapy, ergo therapy, etc.) forces people with disabilities to use their cash benefits, or even incur OOP payments, in order to cover the cost of such LTC services.

The provision of LTC services is characterised by many weaknesses, affecting vulnerable children in multiple ways. Inadequacies in accessibility and availability in some LTC services appear to affect children with disabilities and children of migrants from third countries

[500] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

[501] The Ageing Working Group (AWG) of the EU Economic Policy Committee. The baseline scenario, or AWG reference scenario, focuses on the impact of demographic changes on the budget. The AWG risk scenario takes into account non-demographic factors that drive costs in LTC.

(including undocumented migrants).[502] In order to provide needs-responsive services to this group, the adoption of targeted measures in LTC, rehabilitation, and homecare are deemed necessary. These should address the long waiting times for children with disabilities and the shortage of properly qualified healthcare professionals. In addition, measures are needed to: increase availability and accessibility in relation to rehabilitation services; address the gap identified among children with disabilities aged 1-5; improve the co-ordination of LTC, with more interaction with health professionals; and provide better information about the condition of children with disabilities.

# 3 REFORM OBJECTIVES AND TRENDS

The recent economic crisis further reduced the already very low budget available for LTC, while overloading the public system and increasing waiting lists due to the return of many patients to the free-of-charge public system. On the other hand, it highlighted the need for introducing the new National Health System (NHS), which entered the second phase of its implementation on 1 June 2020 with the provision of hospital care. The new system, financed[503] by the state budget and contributions levied on wages and pensions, will have a positive impact on LTC recipients, as it is expected to increase access to health services[504] and significantly reduce the financial burden of OOP payments. There will be universal coverage and an integrated service package that will provide home, rehabilitation, and palliative care, with particular focus in the inclusion of vulnerable groups.

In 2014, during the period of economic crisis, the government implemented an important reform through the relevant legislation for the introduction of the GMI scheme. The GMI provides a minimum income allowance to every low-income person or family that meets certain criteria, with the aim of guaranteeing a minimum standard of living to everyone. The SWS are responsible for the application of Article 10 of the GMI law, which refers explicitly to the (long-term) care and special needs of recipients.

The GMI legislation clearly sets concrete and measurable criteria regarding eligibility for the benefits paid to GMI recipients, following a rights-based approach. There are specific conditions on the use of cash benefits to pay for homecare. Homecare providers (physical or legal entities) must be approved and registered with the SWS. The register of approved LTC homecare providers is available on the SWS website, along with the specific criteria to be met in order to become an approved provider. New legislation concerning the regulations of the provision of home care is in the process of being adopted.

This is in contradiction to the old regime of public assistance where the scope for discretionary benefits was quite broad, assigning to the director of the SWS considerable freedom in any decision to grant public assistance. It is argued, however, that in the new

[502] Koutsampelas, C., Kantaris, M. and Theodorou M., 'Inequalities in healthcare provision to third country nationals in Cyprus and the prospect of a promising reform', *Migration Letters*, 17(1), 2020, pp. 155-163.
[503] The financing of the new NHS, with a tripartite contribution from beneficiaries, employers, and the state, is estimated at EUR 1 billion – plus an additional EUR 100 million for the needs that arose from the COVID-19 pandemic. The amounts to be directed to LTC are not yet determined.
[504] Inclusion of homecare and certain other services closely linked to rehabilitation and palliative care such as physiotherapy, speech therapy, and ergotherapy as of September 2020.

situation the discretionary power, or at least part of it, has been transferred to the groups of professionals belonging to the SWS, who have the responsibility to evaluate the needs of applicants. According to a 2015 report,[505] the MLWSI remains committed to an ongoing 'fine-tuning process', trying to find the proper mix of a rights-based and a discretionary approach.

During the initial peak of the COVID-19 pandemic (mid-March to mid-May 2020) public sector homecare services were given the additional task of testing and retesting people in self-isolation and quarantine, as well as residents and staff in residential care facilities. This was a particularly challenging and demanding task, to which the staff responded fully. With regards to all other needs for homecare, these were carefully prioritised and limited to absolutely necessary visits. At the same time there was extensive use of telephone communications and teleconsultations both with patients and with other health professionals. With regards to residential care, there were no serious issues or increased cases and, overall, the instructions and decrees of the MoH relating to the control of the virus were observed in all private and public facilities.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

Cyprus needs a comprehensive public LTC system to address the institutional, operational, and funding problems of providing adequate services to those needing constant care. This is required in order to stop households having to take on the financial burden of care through the purchase of services from informal family carers and/or the private sector.

The full implementation of the new NHS will be a major step in this direction. It is expected to significantly improve access and adequacy in relation to specific LTC services. However, policies and infrastructures will need to be better organised and further developed in areas of services that are currently lagging, such as rehabilitation and palliative care, as well as residential and nursing care. This will facilitate and expand access for more potential users of LTC services, who are either on long waiting lists or have given up looking for such services, knowing that they are not sufficient to meet their needs.

In parallel, efforts should be made to seek alternative and complementary sources of funding with the collaboration of both the voluntary and the private sector, provided the roles are clearly defined. At the same time communication and co-operation should be improved between formal LTC providers in order to improve effectiveness and efficiency. Furthermore, community care services should be expanded, along with the education and training of informal carers.

[505] Pashardes, P. and Koutsampelas, C., *ESPN Thematic Report on minimum income schemes, Cyprus*, European Social Policy Network (ESPN), European Commission, Brussels, 2015.

### *Planned reforms and ongoing legislative process and debates*

*(a) The lack of a basic legislative framework that regulates homecare, and the obsolete legal and regulatory framework currently governing residential care, are not helpful in formulating clear criteria and reaching sound conclusions on what is good-quality LTC in Cyprus and how it could be explicitly defined. Two new pieces of legislation for home and community care and residential and daycare are being introduced and are expected to define more clearly the criteria for the registration as well as the qualifications of formal care-givers; these need to be more comprehensive and focus on today's requirements for home and residential care. The SWS anticipates that the new laws will also address the problem of regular reporting of LTC-related data by all private providers, through a standard form.*

*(b) The full implementation of the new NHS is expected to gradually have a positive impact on the accessibility and availability of LTC services since private providers will be able to contract with the new NHS and provide their services to the beneficiaries. The new system includes some LTC services such as homecare, medical rehabilitation, and palliative care. Until now, these services have mainly been provided by the private sector and through OOPs. The limited availability of such services in the public sector forces public health beneficiaries to seek these services in the private sector.*

Since informal care occupies a dominant position in the provision of LTC in Cyprus, it is suggested that a scheme for the compulsory training or up-skilling of informal carers (family members, next of kin, and migrant domestic helpers) should be introduced in order to ensure that this type of LTC (largely unregulated and hard to monitor) is provided by adequately qualified individuals.

Finally, the state should adopt a proactive strategy, with policy approaches aimed at preventing the loss of individual autonomy, thereby reducing the rising demand for care services.

# 5 BACKGROUND STATISTICS

| *5.1. Demographics* | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 0.8 | 0.9 | 1.0 | 1.0 |
| Old-age dependency ratio, 2019 | | 17.9 | 23.8 | 30.1 | 35.3 |
| Population 65+ (in millions), 2019 | Total | 0.1 | 0.1 | 0.2 | 0.2 |
| | Women | 0.1 | 0.1 | 0.1 | 0.1 |
| | Men | 0.0 | 0.1 | 0.1 | 0.1 |
| Share of 65+ in population (%), 2019 | | 12.4 | 16.1 | 19.5 | 22.3 |
| Share of 75+ in population (%), 2019 | | 5.2 | 6.8 | 9.5 | 12.2 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.7* | 20.3 | | |
| | Women | 21.0* | 21.5 | 22.9 | 24.7 |
| | Men | 18.3* | 18.9 | 20.1 | 21.9 |
| Healthy life years at the age of 65, 2018 | Total | 8.8* | 7.5 | | |
| | Women | 7.9* | 6.9 | | |
| | Men | 9.7* | 8.1 | | |

**data for 2010*

| *5.2. People in need of LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 62.1 | 76.8 | 94.2 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 33.1 | 46.4 | 61.8 |
| | Women | | 20.0 | 28.0 | 37.6 |
| | Men | | 13.1 | 18.4 | 24.3 |
| Share of potential dependants in total population (%), 2019 | | | 7.0 | 8.0 | 9.0 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 23.1 | 24.5 | 26.3 |
| Share of population 65+ in need of LTC** (%), 2019* | | 37.5 | 34.3 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| *5.3. Access to LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 4.4 | 4.9 | 5.6 |
| Share of population 65+ receiving care at home (%), 2019 | | | 5.7 | 6.3 | 7.2 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 9.4 | 10.5 | 12.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 43.7 | 45.5 | 48.9 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 40.7 | 43.0 | 45.4 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 38.3 | 30.4 | | |
| | Women | 41.5 | 31.8 | | |
| | Men | 31.1 | 27.2 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 9.1 | 7.1 | | |
| | Women | 12.2 | 10.3 | | |
| | Men | 5.5 | 3.5 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 45.6 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 0.6 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | - | - | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | - | 1.3 | | |
| | % Women | | 90.2 | | |
| Share of population providing informal care (%), 2016 | Total | | 5.2 | | |
| | Women | | 6.1 | | |
| | Men | | 4.2 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 32.7 | | |
| | Women | | 40.6 | | |
| | Men | | 20.2 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.3 | 0.3 | 0.4 | 0.5 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.3 | 0.3 | 0.6 | 1.2 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 3.5 | 5.7 | 5.7 | 5.6 |
| Public spending on home care as % of total LTC public spending, 2019 | 35.1 | 37.1 | 36.5 | 35.2 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 61.4 | 57.1 | 57.9 | 59.1 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.2 | 0.2 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# LATVIA

## *Highlights*

- The population of Latvia declined by 12.4 %, from 2.2 million to 1.9 million, during 2008-2019, and it is expected to fall further to 1.7 million in 2030 and 1.4 million in 2050. This trend is very different from the trend across the EU, where a population decline of less than 0.5 % is expected by 2050. It is very discouraging to see the reduction in healthy life expectancy, by 0.8 years, during 2010-2018 (from 5.3 to 4.5). This could imply greater need for long-term care (LTC) in the future.
- Public spending on LTC in Latvia in 2019 was 0.5 % of GDP compared with 1.7 % in the EU-27, and the share of LTC spending is projected to remain relatively low: 0.5 % of GDP in 2030 and 0.6 % in 2050 (AWG reference scenario[506]). The current low level of public spending on the LTC system means the risks in terms of financial sustainability are low, but it has a potentially negative impact on the quality of LTC.
- Increasing the salaries of doctors, nurses, social workers, and carers in LTC institutions is a key issue for ensuring good quality of care. There is an acute need to increase support to family carers through: flexible working conditions; respite care; different community-based services; and allowances to replace lost wages or cover expenses incurred due to caring.
- The legal and regulatory framework for LTC has been elaborated, including increasing the diversity of service provision to involve non-governmental organisations (NGOs), the private sector, and private-public partnerships (PPPs). A new type of social centre will start functioning in 2020 in Riga, combining the functions of a medical centre, a social service centre, a daycare centre, and social residential accommodation.
- LTC services depend on the financial capacity of service-users themselves and of municipal budgets, which vary greatly within the country – between Riga and its surroundings and the municipalities in many rural areas, especially in the eastern part of the country. Co-financing from municipalities is crucial: in 2018, municipalities fully or partially paid for 96 % of the costs of social care.

[506] A scenario used for projections by the Ageing Working Group (AWG) of the EU Economic Policy Committee.

# 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

## 1.1 Demographic trends

The population of Latvia declined by 12.4 % during 2008-2019, from 2.2 million to 1.9 million. It is expected to fall further to 1.7 million by 2030, and then by a further 17.4 % to 1.4 million in 2050.[507] This trend is very different from the general trend across the EU, where a decline in population of less than 0.5 % is expected by 2050. Although the total number of people aged 65 and over was practically the same in 2019 and in 2008 (0.4 million), their proportion in the population has increased by 15.3 % from 17.6 % in 2008 to 20.3 % in 2019, and is projected to increase to 24.9 % in 2030 and 31.2 in 2050 (higher than the EU-27). The share of the population aged 75 and over has increased even more considerably: by 37 % from 7.3 % in 2008 to 10 % in 2019, and is expected to grow to 11.7 % in 2030 and to 17.6 % in 2050 (the increase over the period 2008-2050 would be 120 %). These proportions are quite similar to those for the EU-27. The old-age-dependency ratio has increased from 25.7 in 2008 to 31.7 in 2019 and is projected to increase rapidly to 41.2 in 2030 and 56.7 in 2050 (compared with 52.0 in the EU-27). Over the period 2010-2019, the increase in life expectancy at age 65 equalled 1.3 years (from 16.1 to 17.4); however, the Latvian numbers are still below the EU-27 life expectancy of 20 years (2018). It is very discouraging to observe the reduction in healthy life expectancy at age 65, of 0.8 years during 2010-2018 (from 5.3 to 4.5) – contrary to the trend in most other EU-27 Member States, as the EU-27 average improved by 1.5 years over the same time period.

The ageing of the population puts the Latvian LTC system under considerable demographic pressure in terms of greater demand for LTC and, at the same time, fewer resources – staff and tax money – to secure the future supply of LTC. The present (2019) number of potentially dependent people (171,300) is projected to fall slightly by 2030 (to 168,200), and fall further by 2050 (160,300). Although the number of potentially dependent people is expected to fall in absolute terms, their share of the total population would grow from 9.0 % in 2019 to 9.9 % in 2030, and 11.5 % in 2050.

In 2019, 38.8 % of people aged 65 and over were in need of LTC (defined as having at least one severe difficulty in personal care and/or household activities).

## 1.2 Governance and financial arrangements

There is no explicit and separate LTC insurance scheme in Latvia. There is a horizontal sharing of responsibilities between the healthcare and social care sectors in terms of regulation, funding, and service provision. LTC for older people provided by healthcare professionals (such as nurses, physiotherapists, and general practitioners) is regulated and funded at the national level. Social care for older people, which includes care services that are aimed at helping care-dependent people carry out activities of daily life (such as household tasks, eating), is funded and regulated at the local level. The Social Services and Social

[507] All the data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.

Assistance Law (2003) is the umbrella law for social care. It provides definitions of social care, residential LTC, and other forms of social care, such as homecare, daycare centres for people with disabilities, and group houses (apartments) for people with mental disorders. Social services are organised and provided in a decentralised way.

The national public administration is responsible for making policy and drafting laws, but local municipalities provide the services and develop local regulations. The municipalities are expected to ensure similar levels of quality and service to those stated in the national laws, regardless of their geographical location, population density, and available budget. All types of LTC for older people (residential care, social care centres, homecare, daycare centres, respite services, etc.) are the responsibility of the municipalities; while long-term residential social care for people with mental disorders (children as well as adults), and LTC for chronic psychiatric patients, are the responsibility of the Ministry of Welfare and the Ministry of Health.

The cost of social care in residential care centres for older people (in Latvia these are called 'social care centres') is borne by the recipients themselves, their family members, and the local authorities. Children have a legal obligation to care for their parents, even to cover the expenses of care in residential care centres. Local municipalities cover all social care expenses for very poor people with an income below EUR 128 per household member per month and without family members to support them financially. The municipalities may set a higher income threshold in order to ensure free services to a wider group of the population, but the generosity of the support depends on the municipality's financial situation and policies.

Depending on the municipality, additional services are offered to support independent living by older people and people with disabilities. Providing support for older people resulted in a 44.2 % growth during 2014-2018 in spending on long-term residential care and homecare. Spending on residential care is the dominant element (70 % in 2014 and 63 % in 2018). However, there was a doubling of spending on homecare, from EUR 10,884,400 in 2014 to EUR 22,031,100 in 2018. Spending on homecare as a share of total local government spending increased by 8 p.p., from 20 % in 2014 to 28 % in 2018.[508]

## 1.3 Social protection provisions

Eligibility for publicly funded LTC services is subject to the care needs of dependent people, their income and assets, and the availability of family carers. To define care needs, a home visit is usually carried out by the social services. The assessment of care needs is increasingly based on a functional assessment, using a scale defining the degree of care dependency. In principle, there is no means-testing threshold for access to homecare. According to the Law on Social Services and Social Assistance, social services shall be provided only on the basis

[508] Ministry of Welfare, *Gada Dati: Pārskati par sociālajiempakalpojumiemunsociālopalīdzībunovada/republikaspilsētaspašvaldībā – 2018.gadā* [Annual data. Report on social services and social assistance in the county municipality of the county/republic cities in 2018], 2019. http://www.lm.gov.lv/lv/publikacijas-petijumi-un-statistika/statistika/valsts-statistika-socialo-pakalpojumu-un-socialas-palidzibas-joma.

of an evaluation of someone's individual needs and resources, carried out by a social work specialist together with a GP. The protocol has six sections: (a) basic needs; (b) mobility; (c) self-awareness, cognitive ability, and security; (d) behaviour and social contacts; (e) personal hygiene; and (f) help in the household. There is a specific dependency threshold set for each different form of the LTC service. For homecare, dependants are eligible if they are unable to take care of themselves and perform everyday activities.

Municipalities have to provide services to everybody who needs them. The payment scheme for residential care is as follows: 85 % (before 2020 – 90 %) of an older people's pension is used to cover the costs of the residential care centre, and 15 % remains as personal spending money. Other expenses are covered by the state budget. In case of the LTC services financed from the state budget, there is no duty of payment in the case of small children (aged 0-2) deprived of parental care, and children with severe mental disability.

If someone in residential care does not have not enough income, and does not have a spouse or a child who is legally obliged to support them financially, the municipality partially or fully shares the costs of care. The state defines the minimum income remaining after the services received are paid for: this is equal to the monthly minimum wage (EUR 430 in 2018-2020) for the first family member, and half the minimum wage for each additional family member. The municipalities can change the payment procedures. For example, Riga City Council has introduced vouchers, worth not more than EUR 400 per month for hospital-type residential care centres, and not more than EUR 640 in a family-type social service setting. This means that relatives are free from co-payments. They can make voluntary additional payments if they prefer a more comfortable level of service. However, the case of Riga vouchers is an exception, although it affects a third of the country's population. Most local authorities evaluate the income of children and grandchildren if the amount of the pension is insufficient for placement in a residential care centre, and determine the amount of local government co-payment in each specific case. In cases where there are no relatives, or people's incomes are too low, the municipality covers the difference between the amount of the pension and the maintenance costs.

There are no special LTC cash benefits for older people. However, there is a state benefit for people with disabilities in need of care of EUR 213.43 per month, and EUR 313.43 per month for children with a disability caused by illness. The assessment is based on the ability of people with disabilities to perform daily activities (Barthel index). At the end of 2018, there were 15,425 care benefit recipients (or 8.04 % of all people with disabilities).

## 1.4 Supply of services

The diversification of LTC service-providers has increased. In 2019, there were 860 registered social service providers in Latvia; of these, 53 % were municipalities, 40 % were NGOs, and 7 % were state and outside contractors (providing state-funded long-term residential social care and social rehabilitation services on a contractual basis). In 2018, there were 105 (83 in 2014) municipal residential care centres for older people, with 7192 (5039 in 2014) people living in them; and there were 82 daycare centres – 23 in the cities and 59 in rural municipalities. Daycare centre service-providers include NGOs, various associations and

foundations, and private entities. Municipalities purchase daycare social services from them for children with functional disorders, children from disadvantaged families, people with mental disorders, people of retirement age, and people with dementia. In 2018 the total number of care recipients in daycare centres was 22,000.

Riga is in the process of developing a PPP for residential care of older people. The cost for one place in the social care centres in Riga in 2020 was EUR 18.45-20.63 per day, or EUR 6738-7530 per year. In Latvia in 2018, the largest share of residents (57 %, or 5629) received services in settings owned by municipalities. The existing practice regarding the remaining residents is that the municipalities buy in services – 22.5 % (1925 residents) from other municipalities, 13 % (1152) from NGOs, and 7 % (602) from private providers (Ministry of Welfare, 2019). The price range varies from EUR 15 to EUR 25 and even EUR 37 per day of stay (EUR 5475, EUR 9125, and EUR 13,505 per year, respectively), depending on the level of care and comfort offered.

There has been visible progress in developing alternatives to residential care by encouraging homecare. From 2016 to 2018 the number of people aged 65 and over in residential care increased by 805 people from 6387 to 7192,[509] and in homecare by 2333 people from 11,256 to 13,589.[510] The proportion of people aged 65 and over receiving residential care was 1.68 %, and for those receiving care at home it was 2.8 %, in 2016. According to our estimation there was an increase in both indicators, to 1.85 % and to 3.5 %, in 2018.

In 2018, social homecare was provided by municipal social services for 8454 people, by NGOs for 7016, and by private entities for 1284 (Ministry of Welfare, 2019). Most recipients of homecare services (77 %, or 12,925 people) lived in urban areas, and 23 % (3629) lived in rural municipalities.

Informal care provided by family members is common in Latvia. The EU-SILC[511] provides 2016 data about informal carers who provide care or assistance to one or more persons needing help due to long-term physical/mental illness, or physical weakness because of old age – including whether the recipient was a member of the same household or not. 4 % of respondents provided care only to household members, 0.2 % only to those not living in their households, and 3.1 % to a mixture of both. Some municipalities (especially in rural areas) conclude contracts with private persons to provide homecare (696 in 2018). The Law on Social Services and Assistance (Section 23) stipulates that local government must provide counselling and psychological support to family members who care for a relative, as well as training and, if necessary, material support. Municipalities also offer other types of support at home for older people, such as security buttons, hot meal delivery, laundry services, and financial support to people with homecare needs. This support is meant to cover – in part or in full – the household's homecare costs. There is no clear national legislation for this kind of benefit: the conditions and the amount of support vary greatly between the municipalities.

[509]Data from Central Statistical Bureau of Latvia (CSB). http://data1.csb.gov.lv/pxweb/en/sociala/sociala__socdr__aprupe/SDG110.px.
[510] Data from CSB. http://data1.csb.gov.lv/pxweb/en/sociala/sociala__socdr__aprupe/SDG140.px.
[511] European Union statistics on income and living conditions.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Public in-kind healthcare benefits include a wide range of services provided by GPs, specialists, hospitals, and emergency care units. Despite full population coverage, only limited services are available 100 % free of charge. Out-of-pocket expenditure on health as a percentage of the total public expenditure on health in Latvia has been among the highest in the EU-27 for decades: 39.1 % in 2014, 40.45 % in 2015, 43.32 % in 2016, and 41.79 % in 2017.[512]

The recent drop in healthy life expectancy at age 65 by 0.8 years (from 5.3 in 2008 to 4.5 in 2018) is the consequence of low public healthcare financing. The self-reported unmet need for medical examination among people aged 65 and over reduced by 8.6 p.p. from 2008 to 2019, but was still very high in Latvia, at 14.8 % (EU – 3.7 %). For the LTC system in Latvia, it is crucial to increase public healthcare funding to at least 4 % of GDP (and preferably 5-6 %).

There has been an increase in the number of people receiving residential care. The data on the situation as at 31 December 2018 show that there were 418 people (mainly in Riga, with a high proportion diagnosed with dementia) on a waiting list to be placed in residential care centres for older people (waiting time up to six months). During the waiting time, a temporary location is provided in case of acute need.

Municipalities are legally obliged to organise LTC services for older people. The Law on Social Services and Social Assistance declares that social services should be provided on the basis of an evaluation of a person's material resources – income and property. If neither the person nor a family member of theirs is able to pay for the social care or social rehabilitation service, the cost must be covered from the local government budget. Many pensioners find themselves at risk of poverty. The average old-age pension was EUR 330 per month in the fourth quarter of 2018 and EUR 359 per month in the fourth quarter of 2019 – below the AROP[513] threshold of EUR 367 in 2018 (as 60 % of median income). The AROP rate in 2019 among people aged 65 and over was 45.7 %, and among those aged 75 and over it was 53.3 % (EU-27 – 15.5 % and 19.5 %, respectively). Financial reasons for not using professional homecare services were mentioned by 37.9 % of respondents, and the unavailability of services by 16.2 %, in 2016. In 2014, 41.0 % of people in Latvia aged 65 and over experienced difficulties in personal care activities or household activities, which was the highest share among all the Member States (EU-27 – 27.3 %).

In 2018, municipalities paid – either in part or in full – for 96 % of the costs of social care. Financial support by local authorities for homecare doubled during 2014-2018. There has been a significant increase in homecare provision in both cities and rural municipalities. Only 13 rural municipalities (out of 110) did not report spending on homecare in 2018 (74 in 2012) (Ministry of Welfare, 2019). LTC recipients are highly dependent on the financial capacity of

[512] Data from Eurostat.
[513] At risk of poverty.

municipal budgets, which vary greatly within the country. Payments by the municipalities are crucial for ensuring LTC for older people.

In principle, there is no means-testing threshold for access to homecare. There is a specific dependency threshold set for each different form of LTC provision.

For healthcare at home, there are certain reimbursements for relevant medical manipulations paid for by the NHS from the state budget.

## 2.2 Quality

All social service providers are obliged to be registered with the Ministry of Welfare. The register of providers of social services constitutes the basis for quality assessment. The register allows verification of whether the service-provider complies with requirements such as the number and qualifications of staff, and the accessibility of care premises or their adjustment to recipients' needs. A detailed system of criteria for social service providers was developed in 2017.

The Methodological Management and Control Department in the Ministry of Welfare monitors the quality of all social services provided, including in residential care, and the qualifications of service staff. Due to limited resources, only a small number of registered service-providers can be assessed each year. In most cases the quality of services is examined only because of complaints received from recipients or their relatives.

The Health Inspectorate is responsible for the quality control of healthcare services. In 2017, the number of complaints about the quality of healthcare constituted 31 % of the total number of complaints. In 2018, the State Audit Office carried out an audit of whether the Ministry of Health has created preconditions for an effective medical rehabilitation system.

The Cabinet Regulation No 138 on rules for receiving social services and social assistance (2 April 2019) describes in detail the evaluation procedure and criteria for deciding whether someone receives social services and social assistance. In addition, the Ministry of Welfare has elaborated self-assessment guidelines for social service providers that contain general quality criteria for professional (formal) social service providers.

The evaluation of the need for homecare is performed by a team comprising a general practitioner and a social worker. Where personal care is provided by family members, the municipality may provide psychological support, counselling, and training, and, if necessary, material support to these family members. As qualification requirements for informal carers are not defined, there is no assessment of their skills, resources, and so on. Nor is there a national-level system for assessing the needs of informal carers as part of the needs assessment of someone in need of care. The use of material support given for homecare services is neither controlled nor monitored at an institutional level. There is therefore a risk of the abuse of older people.

## 2.3 Employment (workforce and informal carers)

The structure and numbers of those employed in state and contracted-out long-term residential social care facilities are rather similar to those in municipal LTC for adults. In 2018, the total

number employed in state and contracted-out social care centres was 3600, and in municipal and other social care centres for adults it was 3482. The heads of 60 facilities have a second-level professional higher or academic education in social work or charitable social work; 49 have a second-level professional higher or academic education in another profession; and 10 had other educational qualifications. The providers of social services in Latvia are divided into several subprofessions, including social workers, social rehabilitation specialists, social care workers, and organisers of social assistance. Among them, healthcare professionals (735) comprise 10 %, functional specialists (220) 3 %, social workers (194) 2.7 %, social carers (331) 5 %, and social rehabilitators (121) 2 %. The largest group – 2822 carers, nannies, and tutors, or 40 % of all those employed in care facilities – provide care directly to older people with disabilities (Ministry of Welfare, 2019).

Social workers represent the most highly qualified professional group with universal skills, especially in smaller local communities. The compulsory education for social workers includes second-level higher education or a bachelor degree; and for social carers and social rehabilitators, first-level higher education or college-level education. Social workers are supposed to go through a training process annually. An ESF-funded[514] project has contributed to the growth of this professional group, covering the cost of 70 % of annual training courses in 2015-2018. Latvia has a two-year programme for social carers and social rehabilitators provided by the P. Stradins Medical College of the University of Latvia. Carers, nannies, and social educators form the largest group of care-givers, with rather different training backgrounds. Social care institutions must provide 21 hours each year of supervision for social workers, social carers, and managers; and an introductory eight hours of instruction and eight hours of training for others. These requirements are strictly followed. In Latvia, as is the case across the OECD[515] and the EU-27 Member States, most workers are middle-aged women. Women represent more than 90 % of the LTC workforce in Latvia, unchanged since 2011. The median age across the OECD countries is 43. The national residential care centres face a large staff turnover, especially in jobs directly related to customer care: carer, social carer, social rehabilitator, and social worker. The high staff turnover is due to low pay, difficult working conditions, and the low prestige of the caring profession. In 2019, carers' pay was increased by about 10 % in Latvia.

Article 188 of the Civil Law establishes the obligation of adult children to provide for their parents; moreover, this obligation falls in equal parts on all children. The Law on Social Services and Social Assistance provides for homecare to meet the basic needs of people who, due to objective circumstances, are unable to take care of themselves. If personal care is provided by family members, the municipality *'shall support these family members psychologically by counselling and training them and, if necessary, also materially'* (Article 23). Possible material support is determined by the local government in binding regulations. Section 8 (paragraphs 4-5), of the Social Services and Social Assistance Law stipulates that if a care recipient or a family member of theirs is unable to pay for a social care or social

[514] European Social Fund (ESF).
[515] Organization for Economic Co-operation and Development.

rehabilitation service, the service costs are covered from the local government budget in accordance with the procedures specified by Cabinet Regulation No 275.

People who care for dependent adult family members have no legal status in Latvia; they are not covered by old-age insurance and are not eligible for paid leave in the event of an emergency. People of working age and children aged 5-18 with severe disabilities have the right to an assistant service provided by the municipality and financed by the state. An assistant is someone who provides support to people with a severe or very severe disability to perform activities outside the home – to get to the place where they study, work, or receive services. Assistants receive payments from the state budget for the hours spent accompanying someone with disabilities, but not for caring for them. If the assistant has an employment contract for normal working hours (40 hours per week), the state guarantees a salary at the minimum monthly level. However, the services of an assistant do not apply to homecare. At present, it depends on the discretion of their employer whether they can have a few days or weeks of unpaid leave. There is a special benefit for someone with a disability in need of care (EUR 213).

A large proportion of care at home is provided informally by family members, relatives, or neighbours. In 2016, the share of people spending 20 or more hours per week on providing informal care or assistance was 33.7 % in Latvia (26.3 % for men and 37.6 % for women) which was much higher than in the EU-27 (22.2 %). The number of formal home-based care workers and nurses is insufficient.

## 2.4 Financial sustainability

Public spending on LTC in Latvia in 2019 was 0.5 % of GDP, which was much lower than the EU-27 average (1.7 % of GDP) according to the 2021 Ageing Report[516]. Spending on feeding per person per day amounted to EUR 2.50 in state-financed residential care centres, and EUR 2.95 in municipality-financed centres in 2018 (Ministry of Welfare, 2019). Projections for Latvia are for spending of 0.5 % of GDP in 2030 and 0.6 % in 2050 in the AWG reference scenario (as opposed to 1.9 % and 2.5 % in the EU-27). The AWG risk scenario involves a more rapid increase of LTC spending in Latvia than in the EU, but even so its share of total spending is expected to be half that in the EU-27 in 2050 (1.7 % in Latvia compared with 3.4 % in the EU-27).

The evolution of the split of LTC expenditure among the three major subgroups of spending – residential care, homecare, and cash benefits – demonstrates the dominance of spending on residential care, albeit with a significant fall in its share during 2013-2050. Its share was 78.9 % in 2013 and 53.4 % in 2019, and is expected to be 55.7 % in 2030 and 59.8 % in 2050. The share of homecare increased from 5.9 % in 2013 to 13.8 % in 2019 and is projected to increase further to 14.3 % in 2030 and 14.4 % in 2050. This will bring Latvia closer to the EU-27. Public spending on cash benefits as a share of total LTC expenditure was 32.7 % in 2019, and is projected to fall slightly to 30.0 % in 2030 and 25.8 % in 2050. In 2018, LTC

[516] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

public spending on healthcare was equivalent to 0.3 % of GDP, and social financing schemes 0.2 %. Household out-of-pocket payments related to LTC amounted to around 0 % of GDP in 2018.

Since total public spending on LTC is comparatively low (0.5 % of GDP in 2019) and the projected future values are also low even in the risk scenario (1.7 % in 2050), it seems that the system is quite sustainable financially. At the same time, it means that there is almost no room to cut spending.

All types of LTC for older people are the responsibility of municipalities, while long-term residential social care for people with mental disorders is the responsibility of the Ministry of Welfare and the Ministry of Health. Public spending on LTC in Latvia is much lower than in the majority of other Member States. Whereas the EU-27 spent 1.7 % of GDP on LTC in 2019, spending in Latvia was much lower – only 0.5 %.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Latvia began a de-institutionalisation (DI) process in 2015 and DI projects are expected to be completed in 2023. The strategy is aimed at moving people with mental disorders from large state-financed residential settings to community-based services. The target groups include: (a) adults with mental disorders living in municipality- or state-financed residential care centres; (b) children in out-of-family care, up to age 18, living in childcare institutions; and (c) children with disabilities, living in families providing support to them and their parents.

The process is financially supported by the EU structural funds (EUR 91 million). In 2019, 21,992 adult residents in Latvia were diagnosed as having a disability due to a mental disorder. Of these, 4496 currently receive services in long-term residential care centres, where they have very limited opportunities for self-determination over their lives. Under the DI process, it is planned to expand the availability of community-based social services necessary for these people. The share of community-based social services should therefore be significantly increased, while care in institutions will be reduced. At the start of the process, this ratio was 20:80 (out of all people with mental disorders who received social services, 20 % received community-based social services).

It was planned that 700 adults with a mental disorder will leave LTC centres within five years, choosing a place of residence in the municipalities, where the necessary conditions for an independent life would have been created. The number of recipients in group housing (apartments) for people with mental disorders increased from 200 in 2016 to 253 people in 2018.[517] However, there is some delay in providing infrastructure. There is still the challenge of changing public attitudes toward people with mental disorders, despite regular communication campaigns and events.[518]

[517] CSB annual data on local government social services, SDG141. http://data1.csb.gov.lv/pxweb/en/sociala/sociala__socdr__aprupe/SDG141.px); Ministry of Welfare, 2019.
[518] https://cilveksnevisdiagnoze.lv/en

Among other things, a wide range of services is being created so that children living in residential care centres can grow up in a family environment, and children with functional disorders can receive social care and rehabilitation in their municipality. Respite services help families in caring for children with severe disabilities: specialists take full care of child for 30 days per year. Parents of children with disabilities up to age 4 can receive support of up to 50 hours of care per week according to special rules.

The efficient use of medical rehabilitation services for patients **of working age** has been scrutinised by the State Audit Office. As a result, the NHS decentralised rehabilitation services into daycare facilities, and doubled the number of rehabilitation centres providing day-to-day rehabilitation services, while halving patients' co-payments in 2019. This facilitated **access to rehabilitation.** Waiting times for inpatient services vary from 4 to 29 weeks. **Post-stroke patients** may receive home rehabilitation.

# 3 REFORM OBJECTIVES AND TRENDS

In 2017-2019, the Ministry of Welfare and the Cabinet of Ministers elaborated laws and regulations to improve the financing arrangements for state-financed long-term social care and social rehabilitation services relating to the level of care, and the control of quality and access in respect of LTC. This secondary legislation helped to bring clarity to stakeholders, care-givers, and care recipients about the further development of LTC in Latvia.

All forms of care for older people are under the responsibility of local authorities, while social care for people with mental disability and LTC for chronic psychiatric patients are under the competence of the central government. This system has generated conflicting interests between different levels of political power. Problems stem from separate budgets used to finance different services and client groups, the organisation of service delivery, and the existence of several bodies involved in the healthcare and social care sectors. Cabinet Regulation No 138 (2019) clearly defines the target groups for whom the state should finance social rehabilitation services. From 2019 the state has allocated grants to local authorities that provide services to people entitled to state-funded long-term social care at the place of their residence. EU funds have been made available to the local authorities to adjust the infrastructure and ensure the availability of services for people with mental disorders and children with disabilities who have opted to receive them at home.

The register of providers of social services constitutes the basis **for quality assessment** and has been publicly available since 2017.

In the amendments to the Cabinet Regulation No 288 on **the procedure for receiving social services and social assistance** (which came into force on 1 December 2017), four levels of care have been defined in accordance with the severity of physical and/or mental disability. Depending on their capacity limits, people are entitled to receive services of the appropriate level of care. All these measures involve much closer co-operation between family doctors, municipal authorities, and social service providers to help older people to receive homecare support for as long as possible or to opt for relocation to residential care.

***COVID-19***

*Thanks to timely action, the number of infections and deaths from COVID-19 in Latvia is one of the lowest in the EU-27. By 1 July 2020, the total number of infections was 1121 (or 595 cases per million of population), and the number of deaths was 30 (16 deaths per million of population).*

*In general, Latvia has coped well with COVID-19 disease control in residential care centres. A total of 90 cases of COVID-19 have been detected in 12 residential care centres: 22 of them were infected employees and 68 were nursing home residents. In May 2020 the largest number of infected people (44) was in the Mārsnēni residence, six of them employees. Of the 30 people who had died in Latvia with COVID-19 by July 2020, nine were related to residential care centres. During the emergency situation (from 12 March 2020 till 9 June 2020) all such institutions were closed for visitors and did not accept new residents. All the staff and the residents were tested for the virus.*

*To support epidemiologists, public health professionals, physicians, pharmacists, and other specialists directly involved in reducing the spread of COVID-19 (and thus working in high-risk and high-load settings), on 26 March 2020 the government decided to allocate EUR 8 million to provide remuneration supplements for three months of 20-50 % of the monthly salary depending on different criteria.*

*For the period from 1 April to 31 May 2020, the Riga City Council used its reserve fund to pay bonuses (of 20 % of the average monthly salary) to employees involved in resolving COVID-19 issues and preventing any consequences. Employees who dealt directly with COVID-19 patients received bonuses of up to 60 % of their monthly salary.*

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The prognosis of the OECD[519] is that declining family size, increased geographical mobility, and the increased participation of women in the labour market will reduce the supply of informal care providers in the future, leading to an increase in the demand for formal care services. At present there is an acute need to further improve the status of informal carers and, in the case of LTC, to provide them with regular respite.

In Latvia most of the responsibility for LTC falls under the Ministry of Welfare; however, it is shared with the Ministry of Health and also in some respects with the Ministry of Regional Development and Environment (concerning planning, provision, and financing). The improvement of co-ordination among ministries is a serious challenge and an opportunity for the development of the system. Local authorities are very active stakeholders, especially in urban areas, buying LTC services from NGOs and the private sector. The role of the private sector is increasing in LTC provision. Riga City Council is in the initial stage of actively developing a PPP to provide LTC in residential care. This represents both a challenge to the

[519] Cravo Oliveira Hashiguchi, T. and Llena-Nozal, A., 'The Effectiveness of Social Protection for LTC in Old Age: Is social protection reducing the risk of poverty associated with care needs?', *OECD Health Working Papers*, No 117, OECD Publishing, Paris, 2020. https://doi.org/10.1787/2592f06e-en

LTC system and an opportunity for change. Systematic monitoring of care processes by the Ministry of Welfare, and evaluation of public policies in the field, would be rather useful.

The growing spending on residential care centres for older people may become a rather challenging issue for municipalities in future. The burden on municipal budgets is expected to increase due to population ageing and depopulation. Some municipalities have found their own ways to reduce spending and provide care to those in need: older people get what can be defined as an innovative solution. To those living in remote farms, when their need for care becomes daily, the municipality offers social houses for accommodation in separate apartments. The municipality covers rent and heating expenditure, provides social carers and access to a doctor and other services, but people pay for other expenses themselves. Such an approach is rather cost-effective for the municipality's budget and friendly to older people with disabilities. A new type of multifunctional social centre for adults was due to start operating in Riga in 2020. It combines the functions of a medical centre, a territorial centre of the social service, a daycare centre, and social residential building where a large proportion of the apartments are specially equipped for people with disabilities.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 2.2 | 1.9 | 1.7 | 1.4 |
| Old-age dependency ratio, 2019 | | 25.7 | 31.7 | 41.2 | 56.7 |
| Population 65+ (in millions), 2019 | Total | 0.4 | 0.4 | 0.4 | 0.4 |
| | Women | 0.3 | 0.3 | 0.3 | 0.3 |
| | Men | 0.1 | 0.1 | 0.2 | 0.2 |
| Share of 65+ in population (%), 2019 | | 17.6 | 20.3 | 24.9 | 31.2 |
| Share of 75+ in population (%), 2019 | | 7.3 | 10 | 11.7 | 17.6 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 16.1* | 17.4 | | |
| | Women | 18.1* | 19.4 | 20.7 | 23.3 |
| | Men | 13.1* | 14.4 | 16 | 19.0 |
| Healthy life years at the age of 65, 2018 | Total | 5.3* | 4.5 | | |
| | Women | 5.5* | 4.7 | | |
| | Men | 4.8* | 4.2 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 171.3 | 168.2 | 160.3 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 104.3 | 112.3 | 120.9 |
| | Women | | 71.9 | 75.2 | 76.2 |
| | Men | | 32.4 | 37.1 | 44.7 |
| Share of potential dependants in total population (%), 2019 | | | 9.0 | 9.9 | 11.5 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 26.7 | 26.3 | 27.8 |
| Share of population 65+ in need of LTC** (%), 2019* | | 41.0 | 38.8 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 1.9 | 1.9 | 2.1 |
| Share of population 65+ receiving care at home (%), 2019 | | | 2.9 | 2.8 | 2.6 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 1.3 | 1.3 | 1.2 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 17.7 | 17.8 | 17.1 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 5.0 | 4.9 | 4.4 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 25.5 | 23.4 | | |
| | Women | 24.0 | 26.2 | | |
| | Men | 30.3 | 13.0 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 5.7 | 6 | | |
| | Women | 6.9 | 7.2 | | |
| | Men | 3.2 | 3.5 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 37.9 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 16.2 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 281.0 | 274.2 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | - | - | | |
| | % Women | | - | | |
| Share of population providing informal care (%), 2016 | Total | | 7.3 | | |
| | Women | | 8.7 | | |
| | Men | | 5.7 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 33.7 | | |
| | Women | | 37.6 | | |
| | Men | | 26.3 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.6 | 0.5 | 0.5 | 0.6 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.6 | 0.5 | 0.7 | 1.7 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 78.9 | 53.4 | 55.7 | 59.8 |
| Public spending on home care as % of total LTC public spending, 2019 | 5.9 | 13.8 | 14.3 | 14.4 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 15.2 | 32.7 | 30.0 | 25.8 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.3 | 0.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.1 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.1 | 0.1 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# LITHUANIA

## *Highlights*

- The provision of the necessary resources for long-term care (LTC) will become more challenging as the demographic old-age-dependency ratio is projected to increase in Lithuania by more than the EU average, while healthy life expectancy at age 65 is falling, contrary to EU-27 trends. Moreover, there are important regional differences in population ageing across the country. The ageing of the population of rural women will increase demand for LTC in the countryside and deplete informal care resources.
- In the formal sector, public care services for older people predominate. There is also the constantly growing sector of non-governmental organisations (NGOs) providing services for older people, while the private market for service provision is still in the early stage of development.
- Recipients of formal social care account for only approximately one third of those receiving care, with a large majority of people receiving informal care from their family members. Informal care will remain important in the future, as there is a constitutional obligation in Lithuania for adult children to take care of their older parents. According to surveys, a large fraction of people aged 50-65 would consider caring for relatives after finishing their professional careers, if they received an appropriate payment for this. Around one fifth of the country's population is currently in the above age group. Hence, there is a need to develop a public support system for informal care-givers in Lithuania.
- Despite the growing coverage of homecare services, most municipalities cannot offer a sufficient package of home-help to enable older people with severe needs to live at home independently. In these cases, older people, if they can afford it, are forced to search for private service-providers or cheaper undeclared workers, or stay on a waiting list for residential care with an average waiting time of six months.
- The attractiveness of work in the formal care sector, especially in home-help services, is undermined by poor working conditions, a stressful working environment, and the lack of development opportunities. Lithuania, like many other EU-27 Member States, faces problems related to the ageing of employees in the healthcare and social work sectors.
- National quality standards are applied to many LTC services, but the monitoring of quality is still not fully functioning (primarily because of the lack of resources for this activity) and focuses primarily on quantitative indicators. The lessons learned from the COVID-19 pandemic showed that there is a need to develop models for remote provision of LTC services, and technologies that would ensure the confidentiality of such services. Furthermore, the control and supervision of the safety of residents and staff in old-age homes, nursing hospitals, and home-help facilities need to be strengthened.

# 1 DESCRIPTION OF THE MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

## 1.1 Demographic trends

The old-age-dependency ratio (based on the population aged 65 and over) is projected to increase in Lithuania by more than in the EU-27 (from 30.4 % in 2019 to 41 % in 2030, and to 56.5 % in 2050).[520] Lithuania belongs to a group of central and eastern Member States with rapidly ageing populations because of emigration and low fertility rates.[521]

Nevertheless, life expectancy at age 65 in the country remained lower than the EU-27 average in 2019 (17.9 years in Lithuania and 20.2 in the EU-27), and especially for men (14.8 years in Lithuania and 18.4 in the EU-27). The indicator 'healthy life years at age 65' fell in Lithuania from 6.5 in 2008 to 6.0 in 2018 (whereas it increased from 8.4 to 9.9 in the EU-27).

There are important regional differences in population ageing across the country. Not only is the rural population much older, but the younger age cohort there is considerably smaller due to external and internal migration; moreover, rural demographic ageing is much more feminised. These circumstances indicate that there will be a rapid increase in demand for LTC in rural areas, combined with depleting informal care resources. The highly deformed age structure of the population in rural areas and small towns, as well as in some shrinking cities, indicate challenges of population ageing and an expected intensive demographic decline in the future (Stankūnienė et al., 2016).

The share of potential dependants in the total population was 8.7 % in 2019 and the forecast figures for 2030 and 2050 are 9.6 % and 11.7 %, respectively. However, the share of the population aged 65 and over in need of LTC, defined as having at least one severe difficulty in personal care and/or household activities, was 34.8 % in Lithuania in 2019.

## 1.2 Governance and financial arrangements

LTC in Lithuania is a relatively new and developing social policy area. Some general principles for LTC can be found in the national strategy for overcoming the consequences of ageing (2004),[522] the Law on Local Self-Government (2008),[523] and the Law on Social Services (2006).[524] Those documents emphasise the need to develop LTC services for older people and people with disabilities to enable them to live at home independently for as long as possible. The operational definition of LTC was not formalised until 2007.[525]

[520] All data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.
[521] Stankūnienė V., Baublytė M., Žibas K. and Stumbrys D., *Lietuvos Demografinė Kaita: Ką atskleidžia gyventojų surašymai* [Demographic development of Lithuania. What do the population censuses reveal?], Kaunas, Vilnius, 2016.
[522] Decision of the Lithuanian Government to adopt the national strategy for overcoming the consequences of ageing [LRV nutarimas Dėl nacionalinės gyventojų senėjimo pasekmių įveikimo strategijos patvirtinimo], 2004.06.14, No 737.
[523] Law on Local Self-Government [Lietuvos Respublikos vietos savivaldos įstatymas], X-1722, 2008-09-15, Žin., 2008, No 113-4290 (2008-10-01).
[524] Law on Social Services (2006). Žin. 2006, No 17-589, i. k. 1061010ISTA000X-493. https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/TAIS.270342/asr
[525] LTC is defined as the entirety of care and social services by which the care and social needs of people are met and continuous comprehensive help and supervision by specialists are provided.

There are two main national institutions sharing the responsibility for the development and administration of LTC policies: the Ministry of Social Security and Labour (MoSSL) is responsible for social care, while the Ministry of Health (MoH) is responsible for healthcare services.[526] LTC in the healthcare sector consists of inpatient services provided in separate nursing hospitals or nursing departments in general hospitals. Agencies licensed to provide primary outpatient healthcare services can also provide home nursing services. The social component of LTC covers daycare facilities, home-help, residential care for older people, and cash-for-care benefits.

Municipalities are directly responsible for the assessment of social care needs and the organisation and provision of social care and primary healthcare. As there is no special (separate) legislation for LTC, all services are integrated either in the healthcare system or welfare social services. It should also be noted that although the organisation and provision of social care services are independent functions of municipalities, their development across municipalities differs substantially.[527]

In 2019, public spending on LTC accounted for 1.0 % of Lithuania's gross domestic product (GDP). The sources of funding are the central government budget, local budgets, and the health insurance fund. Recipients of LTC social services have to contribute to the financing of the services. Their share is calculated on the basis of their income, and even on the basis of the value of their property in the case of residential care. Municipalities have the right to relieve someone from payment for LTC services, and each municipality has its own criteria and regulations for this. The health insurance fund finances nursing services at home as well as long-term medical treatment in healthcare facilities for a period of up to 120 days per year. Stays in nursing facilities that are longer than 120 days per year are paid for by municipalities or by the service recipients themselves. There is no time limitation for palliative care in nursing hospitals.

Household out-of-pocket payments for LTC, as a share of total current healthcare expenditure in 2017, stood at 0.33 % for the 'health' part and at 1.0 % for the 'social' part. These shares have been constantly increasing since 2008.[528]

## 1.3 Social protection provisions

There are different entitlement and eligibility conditions for the 'health' and 'social' parts of LTC services. The assessments of needs and the level of dependency required for LTC also differ between the two systems.

The following people are entitled to social services: (a) Lithuanian citizens; (b) foreigners, including stateless people, holding a permanent or temporary residence permit in Lithuania; and (c) other people in the cases provided for in international treaties (Law on Social Services, 2006). In the social sector, services are provided irrespective of age, but the level of

[526] MoSSL Regulations. Available at https://socmin.lrv.lt/lt/administracine-informacija/nuostatai. MoH Regulations, Available at https://www.e-tar.lt/portal/lt/legalAct/TAR.C9F500A0ED72/asr.
[527] Žalimienė L. and Dunajevas E., *Socialinės Paramos Dilema – Tarp autonomijos ir paternalizmo* [The paradox of social assistance – between autonomy and paternalism], Vilniaus Universiteto Leidykla, Vilnius, 2015, p. 336.
[528] Eurostat data on expenditure for selected healthcare functions by healthcare financing schemes [hlth_sha11_hchf].

someone's dependency is considered. A team of social workers from municipal social services decides which type of social help is needed on the basis of state-regulated criteria. There is no threshold for minimum needs: according to the scale used, someone can be categorised as self-sufficient, partially self-sufficient, or dependent.

Long-term medical nursing services are available for all citizens, with eligibility being based on health insurance coverage. Such services are provided irrespective of age, but take into account the recipient's health condition. The need for long-term medical treatment, nursing care, and palliative care is determined by a physician based on the approved medical indicators.

Lithuania uses three LTC cash-benefit programmes, which may be described as payments to people in need of care to be spent on social services at their own discretion. Persons for whom the Invalidity and Incapacity for Work Service under the Ministry of Social Security and Labor (NDNT) determines the special needs of permanent nursing or special permanent care (assistance) are entitled to targeted benefits.

There are two levels of special needs for continuous care:

(1) Tier 1 special needs nursing care - defined as a person who develops a disability due to persistent, irreversible dysfunction that completely limits his / her autonomy, ability to navigate, and needs continuous care for 8 hours or more;

2) Second level special need for permanent care - determined for a person who develops a disability due to permanent, irreversible dysfunction, significantly limiting his / her autonomy, ability to navigate, and needs continuous care for 6-7 hours a day.

There are two levels of special care / assistance needs:

1) Level 1 Special Needs Continuous Care (Assistance) - Identified by a person who develops a disability due to persistent, irreversible dysfunction, partially limiting his or her autonomy and participation in society, and who needs constant help from others for 4-5 hours a day ;

2) Second level special need for continuous care (assistance) - determined for a person who develops a disability due to permanent, irreversible dysfunction, which slightly restricts his / her autonomy and participation in society, and who needs constant care by others for up to 3 hours a day (help). This is an additional benefit paid in conjunction with a social security or welfare pension.

Both the benefits above are paid to people who are in need according to the defined criteria. If someone is entitled to receive public care services, they have to use these cash benefits to pay for these social services or to pay an informal carer. Finally, *the social care benefit* may be paid in lieu of home-help services if a home-help agency decides that this is a more efficient way to organise assistance (Law on Social Services, 2006). All three types of benefits are cash benefits, paid directly to the dependent people. Benefit recipients are free to choose between public and private providers when using all the aforementioned cash benefits. In case of the social care benefit, its use is controlled at municipal level in line with regulations approved by municipalities. There are no cash-for-care benefits paid to carers in Lithuania.

## 1.4 Supply of services

The main types of LTC services provided in the country include residential services (homes for older people, homes for independent living, daycare centres, nursing hospitals),[529] and homecare services (home-help and community nursing services).

According to national statistics on LTC for 2018, there were about 13,000 older and adult people with disabilities living in residential care homes, about 19,880 receiving social services at home, about 60,000 receiving short-term nursing services at home, and about 18,700 customers of daycare centres.[530] There was a rapid increase in the number of older people using the services of daycare centres up to 2010, but later, because of the economic crisis, the number fell by almost a half during the period 2010-2018.[531]

With regard to the 'social' part of LTC, the balance between residential and home-help services for older people has changed radically since 2005, with an increase in the share of home-help recipients, as compared with residents of care homes[532] (in 2018 the share of population aged 65 and over receiving home-help was 2.6 %, and of those receiving residential care was 1.3 %). However, it should be noted that the lack, and insufficient reliability, of statistical data on LTC recipients in the healthcare sector do not allow strong inferences to be drawn about the exact structure of LTC.

In the formal sector, public care services for older people predominate, though recent years have also seen the appearance of some private providers of these services. The increasing number of requests to issue licences for new care homes for older people indicates that private businesses are interested in this sphere (out of 20 legal entities who requested new licences in 2019, 14 were private firms).[533] There is also a constantly increasing number of older people and people with disabilities receiving social services from NGOs, especially since 2007 with the promotion of social service direct funding without public tenders, which prompted the formation of a mixed social service market.[534] The number of employees in residential care for older people and adults with disabilities increased by 12 % during the period 2014-2018 and amounted to around 8000 people.[535] There are no statistics on the number of nurses and nursing assistants who provide LTC services.

According to the available data for Lithuania, the number of recipients of residential social care and home-help services is only approximately one third of those receiving informal care

[529] There are different governance and service structures provided in these different types of facilities: in homes for independent living, people carry out their household activities independently with the assistance of social workers, while in homes for older people all services are carried out by the staff and the living environment is less similar to that of a regular home (Catalogue of Social Services, 2006). Both types of facility come under the MoSSL, while nursing hospitals come under the MoH.
[530] https://osp.stat.gov.lt/informaciniai-pranesimai?articleId=6429196
[531] Official statistics portal at: https://osp.stat.gov.lt/statistiniu-rodikliu-analize#.
[532] Most of the available official data are on the 'social' component of LTC, which falls under the competence of the MoSSL.
[533] 'Ar Lietuvai reikia kuo daugiau privačių senelių globos namų, kad paslaugų trūkumo problema mažėtų?' [Does Lithuania need more private old-age care facilities to reduce the problem of service provision?] LRT radijas press report. https://www.lrt.lt/naujienos/lietuvoje/2/1139800/ar-lietuvai-reikia-kuo-daugiau-privaciu-seneliu-globos-namu-kad-paslaugu-trukumo-problema-mazetu#.
[534] Žalimienė, L. and Lazutka, R., 'Socialinės globos paslaugos lietuvoje: nuo hierarchinio prie mišrios globos ekonomikos modelio' [Social care services in Lithuania: from the hierarchic to the mixed economy of care pattern], *Pinigų Studijos: Ekonomikos Teorija ir Praktika*, 2009/2: 22-36, 2009.
[535] Official Statistics Portal, at: https://osp.stat.gov.lt/statistiniu-rodikliu-analize#.

from their family members.[536] Most care for older people and people with disabilities is still carried out by informal carers: family, neighbours, friends, and volunteers. However, there is no detailed information about the size and composition of the workforce in LTC. Other research shows that around 40 % of people aged 50-65 look after their older family members.[537] Family members, mostly women, therefore take care of older family members or those with disabilities; alternatively, families are forced to illegally employ care-givers for their relatives.

The growing number (according to surveys) of potential service-users relative to care services in Lithuania indicates the need to develop various employment models, including non-standard forms of employment, in order to ensure better access to in-home services for older people.[538]

# 2 ASSESSMENT OF LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Overall, most municipalities cannot offer a sufficient package of home-help services that would enable older people with severe needs to live independently at home. Hence, such people are forced to find a place in a care home for older people. Access to home-help services is limited, and in most municipalities these services are available only on weekdays and during working hours due to organisational peculiarities of the services (Blažienė and Žalimienė, 2017). According to a national audit study in 2015,[539] only three out of 60 municipalities could provide all kinds of social services for older people. In 2014, 47 % of older people in need of LTC were on a waiting list for residential care, with an average waiting time of six months.[540] Access to LTC services differs across municipalities, as the service network is better developed in some municipalities than in others (Žalimienė and Dunajevas, 2015).

Homecare service coverage has been growing since 2007, which indicates increasing access to it. However, the affordability of LTC services in Lithuania is relatively low, given the need for substantial out-of-pocket spending. According to an evaluation by the Organization for Economic Co-operation and Development (OECD), public support was only about 60 % of the total costs of residential care and homecare for older people with median income and no net total wealth.[541] Only eight other EU-27 Member States report lower public support for LTC.

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[536] *Focus on Skills for Social Care*, Analytical Highlight, EU Skills Panorama, European Commission, 2014. https://skillspanorama.cedefop.europa.eu/sites/default/files/EUSP_AH_SocialCare_0.pdf.

[537] *Transformation of Older People's Care Sector: Demand for services and labour force and quality of work*, Project No GER-012/2015, Lithuanian Research Council, 2017.

[538] Blažienė I. and Žalimienė L., 'Between user's expectations and provider's quality of work: the future of elderly care in Lithuania', *Journal of Population Ageing*, 2017. https://link.springer.com/article/10.1007/s12062-017-9215-1.

[539] *Ar Teikiamos Socialinės Paslaugos Tenkina Didėjančius Senyvo Amžiaus Asmenų Poreikius* [Do available social services satisfy the increasing needs of older people], No VA-P-10-9-10, National Audit Office, 2015.

[540] The Parliamentary Ombudsman has identified major human rights problems in social care settings.

[541] OECD, *Measuring Social Protection for Long-term Care in Old Age: Final Report*, OECD Publishing, Paris, 2019.

Meanwhile, the share of homecare costs met by public social protection is below 40 % for those with moderate needs and below 60 % for those with severe needs, which is less than in most EU-27 Member States.[542] In Lithuania, older people have less than 50 % of their income left after paying for homecare for moderate needs and only 20 % left after paying for severe needs. Hence, they may not be able to afford basic living expenses (especially taking into account the low incomes of older people). According to data on self-reported use of homecare services, the use of such services in Lithuania is half the level of the average resident of the EU.[543]

The abovementioned *social care benefit,* which may be paid in lieu of home-help services if a home-help agency decides that this is a more efficient way to organise assistance, is very rarely used as the organisational mechanism for it has not been properly developed (Žalimienė and Dunajevas, 2015). Furthermore, there are no formal requirements or control mechanisms relating to how the 'target compensation' benefits are used. It can be also assumed that a significant proportion of those receiving the aforementioned benefits do not use formal care services and use the benefits to pay informal carers.

The number of LTC beds and beds per person in nursing facilities was increasing during 2012-2015.[544] The palliative care system is particularly poorly developed. The duration of hospice care is limited to four months per person per year. Besides, the coverage of in-home nursing services is very low as providers of primary healthcare are not interested in their development, due to low payment rates for such services under the mandatory health insurance system. Municipalities are implementing an integrated model of home-based social care and healthcare services for older people. However, while the costs of setting up these services are financed from EU structural funds, the mechanisms for further financing of the running costs of these services remain unclear.[545] So it was decided to continue financing from EU structural funds for the period of 2022-2027. Although home nursing is enshrined in legislation, nursing services at home are not sufficiently guaranteed for residents because of a lack of funding. Insurance coverage for nursing services at home does not meet the real costs, are therefore many healthcare institutions are only interested in providing these services at the minimum level. There are no targeted outreach measures to increase the accessibility of LTC, especially in the healthcare system.

## 2.2 Quality

There are two different quality-assurance systems for LTC, integrated within either the healthcare system or welfare social services (the responsibility of the MoSSL or the MoH). Some quality requirements are enshrined in national law, while others are defined by

[542] OECD, 2019.
[543] Eurostat data on self-reported use of homecare services by sex, age, and degree of urbanisation [hlth_ehis_am7u].
[544] Eurostat data on long-term beds in nursing and residential care facilities. http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth_rs_bds and lang=en.
[545] The possibility of setting up a separate fund for financing integrated home-based social care and healthcare services is under consideration. See: https://socmin.lrv.lt/lt/naujienos/prieinamesnes-paslaugos-senjorams-ir-ju-seimoms-ministrai-prezidentei-pristate-vykdoma-reforma.

municipalities or service-providers themselves. The following LTC quality frameworks in Lithuania can be identified.

- Quality assurance through the standardisation of social care services ('social' part of LTC, responsibility of the MoSSL).[546] It covers residential care services, and some daycare services for older people and people with disabilities.
- National quality regulations of LTC ('health' part of LTC, responsibility of the MoH) (e.g. hygiene norms).[547]
- Local requirements for the quality of home-help services,[548] other types of community-based social services, and primary healthcare services (responsibility of each municipality) (Law on Social Services, 2006). Since January 1 2022 home help services will be acreditated, requirements for accreditation will be introduced by MoSSL.
- Some optional recommendations of the MoSSL for the organisation and provision of home-help services (Law on Social Services, 2006). Municipalities are encouraged to create quality-assurance systems for their services (general social services and community-based social services) by providing certain guidelines and recommendations. The Department of Supervision of Social Services under the MoSSL provides methodological assistance to municipalities regarding quality-assurance indicators and system-building for the aforementioned services.
- MoSSL initiative of quality assurance in social services (implementing the EU structural funds project EQUASS: voluntary European quality framework for social services).

There is no quality assurance for informal care services. The quality of informal LTC services can only be assessed on the basis of research studies carried out in this field.[549]

National standards are applied to residential care homes for older people and daycare centres. These standards apply to all service-providers (public, private, funded with public money or not, for-profit or not-for-profit). A national system is in place for licensing and evaluating the quality of social care in accordance with the standards.[550] Since 2015, all providers of social care services in Lithuania (public, private, NGOs) are required to obtain a relevant licence. Such licences, however, are not required for providing home-help or other general social services. Since 1 July 2020 accreditation of home-help has started. Providers of these services have requirements for staff qualifications and premises (if service premises are required). From 1 January 2022 only accredited social care will be provided (Law on Social Services,

[546] *Description of Social Care Standards*, No A1-46, MoSSL, 2007, https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/TAIS.292682/asr
[547] *Lithuanian Norms of Hygiene*: *HN 125:2011, Residential care institutions for adults – general health requirements,* No V-133, MoH, 2011. https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/TAIS.392765.
[548] Municipalities prepare quality-assurance indicators and monitoring systems independently. For example, the regulations for providing general social services and performing social care quality evaluation approved by the municipal administration of the Kaunas city. https://www.kaunospc.lt.
[549] *Social Research Review* [Socialiniai tyrimai trumpai], 4: 1-8. ISSN 2538-7006. eISSN 2538-7014, Lithuanian Centre for Social Research, 2017. http://epublications.vu.lt/object/elaba:25588265.
[550] There are detailed requirements for ensuring the quality of services in legislation, and service-providers have to comply with these requirements: *Description of Social Care Norms*, MoSSL, 2007. https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/TAIS.292682).

2006). Under the new rules, anyone eligible for home-help will have the opportunity to choose a provider in accordance with the established procedures, while the municipality will be able to conclude an agreement with the chosen provider (or the social service institution providing accredited care) on financing the costs of the services delivered.

The quality assurance of the 'health' part of LTC services is a part of the healthcare system. Medical LTC institutions are supervised by the State Healthcare Accreditation Agency under the MoH. Licensing of healthcare organisations is mandatory by law and licences must be renewed every five years. In addition, patient satisfaction surveys are conducted annually. In 2011, the MoH approved special requirements for geriatric services. Most personal healthcare quality requirements are focused on quantitative indicators (e.g. increasing the number of nursing care beds, setting up more geriatric departments), and do not provide for any qualitative indicators. Accreditation is mandatory for all healthcare institutions. The State Healthcare Accreditation Agency participates in the formation of national healthcare quality policy and performs public supervision of accessibility and quality in relation to personal healthcare services (Law on the Health System, 1994). According to a national audit report,[551] municipalities pay insufficient attention to quality assurance in healthcare. This remains a challenge, with little signs of progress in the sphere.

## 2.3 Employment (workforce and informal carers)

There are no statistics about the size of the formal LTC workforce. Official figures show that the number of workers in residential care for older people and adults with disabilities was 8160 in 2017. There is no consolidated source of information on characteristics of the formal LTC workforce and related problems. For example, data from the Employment Service indicate that there was an increase in the number of social workers and social work assistants looking for work, but, simultaneously, the demand for these workers exceeded supply – suggesting that one of the reasons may be low wages and unattractive working conditions.[552]

Another piece of research shows that Lithuania, similar to many other EU-27 Member States, faces the emergence of problems related to the ageing of employees in the healthcare and social work sectors. The heavy workload of social workers and their assistants, a high level of stress, the risk of burn-out, low pay, and insufficient support the employees receive from their organisations all contribute to the problem.[553] Employment in homecare is characterised by very low wages, frequent unpaid overtime work, the absence of one's own workplace, and safety-related issues. Municipalities very often hire such employees on a part-time basis to save money. Around 60 % of homecare workers point out that they need supervision services, psychological consultations, and additional safety measures. The fact that 64 % of home-helpers have university degrees is indicative of the problem of over-qualification in this

[551] *Asmens Sveikatos Priežiūros Kokybės Užtikrinimo Sistema* [Quality-Assurance System of Personal Healthcare Services], No VA-P-10-4-9, National Audit Office, 2011.
[552] *Kvalifikacijų Tyrimo Ataskaita Socialinių Paslaugų Sektoriaus Profesinio Standarto Rengimui: 2018*, Lietuvos ES struktūrinės paramos projektas, Kvalifikacijų sistemos plėtra, Projekto Nr.09.4.1-ESFA-V-734-01-0001. https://www.kpmpc.lt/kpmpc/wp-content/uploads/2015/08/kvalifikaciju-tyrimo-ataskaita_socialiniu-paslaugu-PS_final.pdf.
[553] Žalimienė, L., Skučienė, D., Junevičienė, J. and Gataūlinas, A., *Profesinė Gerovė Socialinio Darbo Paslaugų Sektoriuje Lietuvoje* [Occupational Well-Being in Social Work Services in Lithuania], Lithuanian Centre for Social Research, Vilnius, 2013.

sector. As the remuneration of employees in this area is fundamentally independent of their level of education, this suggests an inefficient use of the labour force.[554]

According to OECD evaluations, the median age of the LTC workforce across countries is 45, whereas in Lithuania this figure is one of the highest, standing at around 50.[555] There is no certification and licensing of social care workers and nursing assistants, while nurses need to be licensed. The average salary of a personal care worker was around EUR 850 per month in 2017, which is higher than the minimum wage (2020 – EUR 607 per month) (OECD, 2020).

In 2016, the share of population providing informal care was 8.3 %, while 34.6 % of those providing informal care did so for more than 20 hours per week (the EU-27 averages stood at 10.3 % and 22.2 %, respectively).

Lithuania is one of the nine Member States in the EU-27 where adult children providing 22.5 hours of homecare for an older parent do not receive any public support. It means that there is a strong incentive to choose formal care rather than informal care, when considering the costs of homecare for moderate needs (OECD, 2019). Although there is a constitutional obligation on adult children to take care of their older parents in Lithuania, in practice it is not legally enforced.

In 2018, 25.8 % of inactive women in Lithuania were not actively seeking a job due to caring responsibilities (including for children), as compared with only 7.5 % of men.[556] According to the gender equality index, although in general the participation of women in employment in Lithuania in 2017 remained higher than the EU-27 average, the largest decrease in gender equality since 2005 was in the sphere of time use for care and domestic work. This is due to traditions of family care, the insufficient capacity of the formal care sector, and the high costs of private services. At the same time, assistance to informal care-givers is insufficient. There are few public services to help family carers, and insufficient measures to reconcile family care and work. For example, since 2019, people caring for their relatives can apply for respite care services, but only a very small percentage of family care-givers use such services.[557] Since 2020 June 1 only 237 people/families have applied for respite care services. Evaluations also show that care-givers who are employed also lack assistance from the state. According to a survey, 30 % of respondents aged 50-65 stated that the main factors encouraging them to

[554] Žalimienė, L., Blažienė, I. and Miežienė, R., 'Lankomosios priežiūros darbuotojų darbo vietos kokybė Lietuvoje' [Job Quality of Home-help Workers in Lithuania], *Filosofija. Sociologija,* 28 (2), 2017, pp. 151-159. http://mokslozurnalai.lmaleidykla.lt/publ/0235-7186/2017/2/151-159.pdf.

[555] OECD, 'Who Cares? Attracting and retaining care workers for the elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en.

[556] Eurostat data on the inactive population due to caring responsibilities by sex. http://ec.europa.eu/eurostat/tgm/table.do?tab=table and init=1 and language=en and pcode=sdg_05_40 and plugin=1.

[557] There is no in-depth research on the reasons why respite care services are little used in Lithuania. Some explanations can be found in the literature and other sources of information. These include, for example, low levels of trust in formal care among care-givers and the emotional costs of using such services for both care-givers and people in need of care. (Motiejune. A., *Demencija Sergančiojo Globos Seimoje Veiksniai Paslaugų (De)familizacijos Kontekste: 'Isikalinimas' ar 'įkalinimas'* [Factors of homecare provision for a person with dementia in the context of (de)familiarisation of services: 'self-imprisonment' or 'imprisonment'], Master Thesis, VU, 2018).

care for older family members were the possibility of working flexible hours and the possibility of receiving some state support as a care-giver (23 %).[558]

## 2.4 Financial sustainability

Public expenditure on LTC was 1.0 % of GDP in Lithuania in 2019 according to the the 2021 Ageing Report[559], compared with the EU-27 average of 1.7 %. Financing by the government and compulsory contributory schemes as a share of GDP for the health and social parts of LTC was 0.5 % and 0.5 % respectively in 2018. Household out-of-pocket payments as a share of GDP were around 0.0 % for LTC (health) and 0.1 % for LTC (social) in 2018.

There are big differences in the structure of LTC spending between Lithuania and the EU. Whereas the major part of public spending on LTC in Lithuania is spending on homecare (52.3 %), it mainly goes on residential care in the EU-27 (56.0 %). This structure of public expenditure on LTC is forecast to remain unchanged for the period 2030-2050 in Lithuania, with a small increase in the share of spending on homecare and a corresponding reduction in the spending on residential care and LTC cash benefits. These trends also reflect the expectations of Lithuanian citizens regarding LTC in old age. An absolute majority of respondents aged 50-65 see themselves as potential home-help recipients in old age (Blažienė and Žalimienė, 2017).

Reflecting demographic changes, the projected public expenditure on LTC care as a percentage of GDP in Lithuania should steadily increase from 1.0 % in 2019 to 1.2 % in 2030 and 1.60 % in 2050 (reference scenario), or to 1.5 % in 2030 and 3.3 % in 2050 (risk scenario).

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

The 2012 guidelines for de-institutionalising the social care homes of people with disabilities, children deprived of parental care, and adults with disabilities, introduced a priority for the development of community-based services (daycare centres, home-help and homecare services) until 2030. The process of de-institutionalising residential care for people with disabilities faces difficulties mainly with negative attitude towards people with disabilities in society. This causes problems for the development and expansion of community services and integration of people with disabilities into the community. But despite this, the number of adults with disabilities in social care homes is declining from 5,800 to 5,665 between 2015 and 2020. Another 500 people were on the waiting list as of 2017.[560]

[558] Žalimienė L., Blažienė I. and Junevičienė, J., 'What type of familialism is relevant for Lithuania? The case of elderly care', *Journal of Baltic Studies*, Vol. 51, Issue 2, 2020. https://doi.org/10.1080/01629778.2020.1746368.
[559] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.
[560] Statistics Lithuania, Survey of social services. https://osp.stat.gov.lt/statistiniu-rodikliu-analize?portletFormName=visualization and hash=7e5b82e2-2522-4d0c-a230-dc7a0904e84b#/

Coverage of homecare and daycare services for adults with disabilities has remained at the same low level for many years (only about 6 % in 2017).[561] There is little change in the number of children with disabilities who receive social services in daycare centres as well. As of 2017, these services were received by 2217 children with disabilities, making up around 15 % of their total number. Residential care services are provided to around 6 % of children with disabilities.[562]

According to experts, there has been no substantial movement towards de-institutionalising residential care for people with disabilities within the last 30 years, care services are excessively medicated, and there are insufficient alternatives for community-based services.[563] De-institutionalisation for people with disabilities is already being implemented. Currently, 31 group living homes have been established, housing about 250 people with disabilities from inpatient care institutions. Moreover it is planned till 2023 to establish 71 group / independent living houses, which will accommodate not only the disabled people, currently living in institutions, but also people living in the community, who are currently waiting in line for institutional care. With these investments are planned to create 1,088 places to accommodate people with disabilities in the community.

However, there are improvements in the provision of more diverse and better assistive technology, which improves the quality of life. In 2020, the need for assistive technologies was satisfied in 83.37 % of cases.[564]

# 3 REFORM OBJECTIVES AND TRENDS

Most reforms directly or indirectly addressing LTC development are not new reforms, but a continuation of previous ones. A reform on de-institutionalising the social care of adult people with disabilities and children deprived of parental care (which entered into force in 2012) provided for a transition from residential social care to community services by 2030. The action plan for increasing social inclusion 2014-2020 stresses the inclusion of the NGO sector in the provision of social services, the introduction of new social services, and priority for the development of community-based services. Despite the declared priority for community-based services, the process of de-institutionalising LTC for adults with disabilities, is relatively slow. In 2014, the action plan for ensuring healthy ageing in Lithuania 2014-2023 was approved, providing directions for the integrated care and geriatric healthcare services network. The main changes in LTC implementing these documents in Lithuania are de-institutionalisation, the integration of healthcare and social care, and the introduction of quality standards of services.

[561] Idem.
[562] Idem.
[563] Puras, D., 'Deinstitucionalizacija ir su ja susije issukiai Lietuvoje ir platesniame regione' [Deinstituionalisation and its challenges in Lithuania and the wider region], Commentary. https://manoteises.lt/straipsnis/deinstitucionalizacija-ir-su-ja-susije-issukiai-lietuvoje-ir-platesniame-regione.
[564] Centre of Assistive Technology under the MoSSL.

The development of integrated social care and healthcare provision started in 2015.[565] Although many municipalities have implemented the EU-supported model of integrated care for older people at home, the funding mechanism for integrated nursing and care services at home is not yet in place. Programme implementation has been extended to December 2021 to allow for integral care models in all municipalities. However, this area still lacks the required attention and resources, especially within the context of the pressing challenges of the COVID-19 crisis. The legal framework for integrated service provision was initiated in 2007, when the procedure for the integrated provision of nursing and social services was approved.[566] New amendments to this document were prepared in 2017, but the relevant institutions have failed so far to agree on some aspects of integrated service provision. The importance of integrated service provision was also emphasised by the President of the Republic of Lithuania, who initiated the preparation of a new legislation for integrated care in 2019.[567] The concept of LTC services is currently being developed by the MoSSL jointly with the MoH, with the aim of defining joint operations by the social care and the healthcare systems. The plan of measures for the implementation of the provisions of the government program provides for 2024 to prepare draft Law on Long Term Care. Since 1 July 2020 each outpatient healthcare service-provider at home has had an obligation to reach an agreement with a social services at-home provider in order to meet the needs of care recipients better.

In a new personal healthcare quality-improvement programme, approved in 2017,[568] it was admitted that Lithuania is still submitting data for only a small part of the indicators used by the OECD for the evaluation of healthcare quality. It is therefore important to expand the list of indicators. The social services quality-assurance system EQUASS in the sphere of home-help services is under implementation in some municipalities in 2017-2022.[569] However, the implementation of this system is not co-ordinated with or integrated into other existing quality frameworks for social services and is being implemented at the initiative of municipalities.

Some of these reforms address, to a certain extent, the country-specific recommendations (CSRs) for Lithuania. One of the CSRs for Lithuania for 2017-2018 was to '*improve the performance of the healthcare system … increasing the quality and affordability of care'*. According to the evaluation, measures taken to improve the quality of care were partial, targeting only primary care facilities, and limited to the introduction of some monitoring indicators. It is too early to assess whether these measures are sufficient to address quality

[565] Integrated care development programme 2012, 2015. https://www.e-tar.lt/portal/lt/legalAct/TAR.FD286C03D58E; https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/2b93f3a02b2c11e58a4198cd62929b7a/ROXXjayCDs.
[566] *Dėl Slaugos ir Socialinių Paslaugų Bendro Teikimo Tvarkos Aprašo Patvirtinimo* [On the integrated provision of nursing and social services], Sveikatos apsaugos ministro ir Socialinės apsaugos ir darbo ministro įsakymas 2007 m. liepos 4 d. No V-558/A1-183. https://e-seimas.lrs.lt/portal/legalAct/lt/TAD/TAIS.301549?jfwid=-9dzqnu48b.
[567] 'Prezidentė inicijuoja pagalbos pagyvenusiems žmonėms reformą' [The President initiates a reform of help provision for older people]. https://www.lrp.lt/lt/prezidente-inicijuoja-pagalbos-pagyvenusiems-zmonems-reforma/31660.
[568] Personal healthcare quality improvement programme. Order of the Minister for Health of the Republic of Lithuania. November 2017, No V-1292.
[569] Improvement of social services quality by the EQUASS quality system. No 08.4.1-ESFA-V-421-01-0001. Project is being implemented by the 'VšĮ Valakupių reabilitacijos centras': http://www.equass.lt/apie-projekta.

concerns.[570] The CSR for 2019-2020 related to LTC is to increase the quality, affordability, and efficiency of the healthcare system.[571]

Since 2017, there have been no reforms addressing such areas of LTC as affordability, extension of benefits, financing, or reforms aimed at attracting and retaining the workforce in the formal care sector (except for some wage increases, following trade union demands).

It is still too early to speak about the impact of the COVID-19 crisis on the provision of LTC, and on its funding and workforce in Lithuania. During the first nationwide quarantine in spring 2020, contact services provided at the daycare facilities in Lithuania were suspended and people were asked to voluntarily withdraw their relatives from residential care, but during second quarantine from November 2020 contact provision of social services was ensured. More in-depth research and analysis of the short- and long-term effects of this crisis on the provision of LTC is yet to be conducted.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The quality-assurance system for LTC is still not fully functioning, primarily due to a lack of resources. It also focuses on quantitative indicators, whereas it is important not only to include qualitative indicators for the monitoring of the quality of services, but also to provide adequate resources for the evaluation of these indicators.

There is a need for a system of co-ordination and co-operation between various existing and newly implemented quality systems for LTC services (i.e. of national standards on social care services, national regulation of LTC services, MoSSL initiative of EQUASS implementation, local LTC quality regulations).

It is necessary to establish a coherent and integrated legal and governance framework for a clear delineation of the responsibilities of state authorities concerning the provision of LTC services.

Taking into account the high level of out-of-pocket payments by those receiving home-help services, measures could be considered to reduce the risk of poverty among this group of older people such as revising the method of payment for these services and determining the extent of cost-sharing by users of LTC benefits.

There is a need for policies to support informal (working and non-working) carers, for example through flexible working conditions, respite care, and carers' allowances to replace lost wages. It is important to develop the organisational and legal preconditions for implementing cash benefits for carers.

[570] Angerer, J., Ciucci, M. and Tiido, J., *Country-specific recommendations for 2017 and 2018. A tabular comparison and an overview of implementation*, European Parliament, 2019. https://www.europarl.europa.eu/RegData/etudes/STUD/2018/614522/IPOL_STU(2018)614522_EN.pdf.

[571] Council recommendation of 9 July 2019 on the 2019 national reform programme of Lithuania and delivering a council opinion on the 2019 stability programme of Lithuania (2019/C 301/15).

Lithuania is one of the nine Member States in the EU-27 where adult children providing homecare for an older parent for 22.5 hours or more do not receive any benefits. It means that there is a strong incentive to choose formal care rather than informal care. At the same time, some research has revealed that a relatively large fraction of people aged 50-65 would consider providing care for relatives after finishing their professional careers, if they received an appropriate payment. Such a disposition on the part of older people to engage in care-giving activities can be viewed as an important resource for the LTC workforce in the future. It should also be noted that around a fifth of the country's population is currently in the above age group. Hence it is important to conduct more research on the issue.

It is important to improve working conditions for those providing home-help services, as the development of non-standard forms of employment in this sphere may indicate a deterioration in the quality of workplaces (i.e. less stability and social guarantees for workers).

Primary healthcare providers pay little attention to the development of nursing at home: more efficient ways to administer these services should be sought.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 3.2 | 2.8 | 2.6 | 2.1 |
| Old-age dependency ratio, 2019 | | 25.2 | 30.4 | 41.0 | 56.5 |
| Population 65+ (in millions), 2019 | Total | 0.5 | 0.6 | 0.6 | 0.7 |
| | Women | 0.4 | 0.4 | 0.4 | 0.4 |
| | Men | 0.2 | 0.2 | 0.2 | 0.3 |
| Share of 65+ in population (%), 2019 | | 17.0 | 19.8 | 24.9 | 31.5 |
| Share of 75+ in population (%), 2019 | | 7.3 | 9.9 | 11.2 | 18.6 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 16.7* | 17.9 | | |
| | Women | 18.8* | 20.0 | 21.2 | 23.5 |
| | Men | 13.8* | 14.8 | 16.4 | 19.3 |
| Healthy life years at the age of 65, 2018 | Total | 6.5* | 6.0 | | |
| | Women | 6.7* | 6.3 | | |
| | Men | 6.4* | 5.6 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 242.2 | 246.2 | 249.5 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 149.8 | 167.6 | 193.0 |
| | Women | | 105.4 | 115.0 | 124.9 |
| | Men | | 44.3 | 52.6 | 68.1 |
| Share of potential dependants in total population (%), 2019 | | | 8.7 | 9.6 | 11.7 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 27.0 | 26.0 | 28.7 |
| Share of population 65+ in need of LTC** (%), 2019* | | 38.3 | 34.8 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 10.6 | 10.3 | 11.3 |
| Share of population 65+ receiving care at home (%), 2019 | | | 12.4 | 12.1 | 15.3 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 15.6 | 15.4 | 20.2 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 85.1 | 86.1 | 92.6 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 57.6 | 59.1 | 70.2 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 43.1 | 37.2 | | |
| | Women | 44.7 | 40.0 | | |
| | Men | 38.4 | 28.3 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 5.2 | 5.3 | | |
| | Women | 6.3 | 6.3 | | |
| | Men | 3.1 | 3.4 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 42.4 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 5.3 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 643.0 | 726.3 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | - | - | | |
| | % | | | | |
| | Women | | - | | |
| Share of population providing informal care (%), 2016 | Total | | 8.3 | | |
| | Women | | 9.1 | | |
| | Men | | 7.3 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 34.6 | | |
| | Women | | 37.5 | | |
| | Men | | 30.0 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.4 | 1.0 | 1.2 | 1.6 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.4 | 1.0 | 1.5 | 3.3 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 36.2 | 55.5 | 54.6 | 49.9 |
| Public spending on home care as % of total LTC public spending, 2019 | 28.6 | 4.8 | 4.9 | 5.2 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 35.2 | 39.8 | 40.4 | 44.9 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.5 | 0.5 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.4 | 0.5 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.1 | 0.1 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# LUXEMBOURG

***Highlights***

- Luxembourg will experience between 2019 and 2050 one of the sharpest increases in the share of people aged 65 and over among EU-27 Member States.
- In terms of availability, accessibility, and quality, the Luxembourg long-term care (LTC) system is classified among the best-performing countries, according to Eurofound findings; however, this may change in the future with the expected massive increase in the number of beneficiaries.
- Informal carers play an important role, but it is not certain that in future there will be enough people inclined to become informal carers.
- Different scenarios[572] show that wider reforms in the LTC system are still necessary in order to guarantee its financial sustainability.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The present demographic situation of Luxembourg does not fundamentally differ from the other EU Member States. However, due to a significant increase in life expectancy, and despite a sizeable net migration inflow, Luxembourg will experience one of the sharpest increases in the share of people aged 65 and over among EU-27 Member States. Indeed, the share of people aged 65 and over is projected to increase from 14.4 % in 2019 to 25.5 % in 2050; the number of people aged over 65 will double, whereas the total population will show an increase of only one third during the same time.[573]

Luxembourg will also experience an increase in the number of people needing LTC. The number of potential dependants (in thousands) is projected to increase from 55.7 in 2019 to 68.5 in 2030 and to 88.7 in 2050.[574] These figures correspond to the AWG[575] reference scenario.[576]

[572] See reference and risk scenarios in: European Commission, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, European Commission, Brussels 2021.
[573] All data used in the text come from Section 5 'Background Statistics' unless explicitly stated otherwise.
[574] These data are based on the proportion of respondents who report a severe 'self-perceived longstanding limitation in activities because of health problems' from the EU-SILC survey. As the EU-SILC survey concerns only persons living at home, the number of institutional care recipients from administrative data are added.
[575] AWG: Ageing Working Group, a working group mandated by the EPC (Economic Policy Committee, set up by a Council decision in 1974 to provide advice and to contribute to the work of the Economic and Financial Affairs Council and the Commission) to prepare the 2021 Ageing Report.
[576] Data refer to the reference scenario in the 2021 Ageing Report.

## 1.2 Governance and financial arrangements

Compulsory[577] LTC insurance (*assurance dépendance*) came into force on 1 January 1999.[578] The law was amended in 2005, 2017, and 2018.[579] With the introduction of this new insurance, dependency was recognised as a new social security risk, similar to sickness and others. The goal of the insurance is to provide compensation for the expenses generated through third-party assistance to perform daily living activities. This applies not only to the needs of older people, but also to the needs of people with disabilities.[580]

The following guiding principles apply to LTC insurance.

- Priority for rehabilitation measures over taking responsibility for dependency
- Priority for homecare over residential care
- Priority for benefits in-kind over cash benefits
- Continuity in LTC

The LTC insurance is essentially financed by three resources, as follows.

- A dependency contribution levied on the professional and replacement revenues of insured people. This contribution is set at 1.4 %.[581]
- An annual contribution from the state, currently set at 40 % of the total expenses of the LTC insurance scheme, after a deduction for the allocation of the legal reserve.
- An insurance licence fee from the energy sector.[582]

The organisation of the LTC insurance system has been entrusted to two bodies, namely the State Office for the Assessment and Monitoring of the LTC insurance (*Administration d'évaluation et de contrôle de l'assurance dépendance* – AEC) and the National Health Insurance (*Caisse nationale de santé* – CNS).

The AEC is a public service under the authority of the Ministry for Social Security. It ascertains the dependency level of applicants and establishes a summary of care and assistance. The AEC is also in charge of: (a) monitoring the quality of services provided, and

[577] As for other social insurances, employed and self-employed are compulsorily insured. More detail can be found in Articles 1-7 of the social security code (*code de la sécurité sociale* – CSS), Luxembourg, Inspection Générale de la Sécurité Sociale (IGSS), 2020a.
[578] *Loi du 19 Juin 1998 Portant Introduction d'une Assurance Dépendance*, Journal Officiel du Grand-Duché de Luxembourg (JOGDL), Mémorial A, No 48 du 29 juin 1998, Luxembourg, Grand-Duché de Luxembourg, 1998.
[579] *Loi du 23 Décembre 2005*, JOGDL Mémorial A, No 215 du 28 décembre 2005, Luxembourg, Grand-Duché de Luxembourg, 2005; *Loi du 29 Août 2017*, JOGDL Mémorial A 778 du 1 septembre 2017, Luxembourg, Grand-Duché de Luxembourg, 2017a; *Loi du 10 Août 2018*, JOGDL Mémorial A 703 du 21 août 2018, Luxembourg, Grand-Duché de Luxembourg, 2018b.
[580] A global overview of dependency insurance in Luxembourg can be consulted in: *Rapport Général sur la Sécurité Sociale 2019*, IGSS, Luxembourg, 2020b. There also exists a practical guide to LTC insurance before the 2017 reform: Ministère de la Sécurité Sociale, *L'Assurance Dépendance – Guide pratique*, Cellule d'évaluation et d'orientation de l'assurance dépendance, Ministère de la Sécurité Sociale, Luxembourg, 2009.
[581] In 2007, the contribution rate was increased from 1.0 % to 1.4 % on (more or less) all earnings.
[582] This was introduced to compensate for the fact that employers did not have to contribute to this new form of a social insurance, as they had to for pensions and sickness insurance. This fee is indirectly paid by the biggest electricity consumers. Nowadays it is rather symbolic: 0.27 % of total receipts in 2018.

their adequacy in meeting the needs of dependants; and (b) informing and advising LTC insurance beneficiaries and informal carers entrusted with the care of dependants.

The national health insurance system takes individual decisions based on the evaluation of the AEC and informs the beneficiary. The CNS is in charge of the budget for LTC insurance, the disbursement of payments, and the management of the scheme. It negotiates biennially, together with the body representing LTC providers (*Confédération des organismes prestataires d'aides et de soins* – COPAS), the monetary allowances allocated to LTC providers.

In order to operate in the field of LTC insurance, service-providers must practice by virtue of an authorisation issued by the Ministry of Family. They must also adhere to the framework agreement negotiated between the CNS and COPAS, or engage with the CNS through a service contract.

Increased attention is given to informal carers, in order to keep the beneficiaries of LTC insurance integrated within their family. This is done by: assessing the level of assistance they give with activities of daily living and household tasks; providing respite care; and providing training. If the informal carer is no longer able to furnish assistance (for example due to a deterioration in their health), the system allows an easy switch to formal care. A reference document (*référentiel des aides et soins de l'assurance dépendance*) clearly defines the different support categories, and the circumstances under which LTC is granted.

Total public spending on LTC in 2018 was EUR 664.1 million, of which 43.5 % was dedicated to homecare and 50.3 % to residential care (IGSS, 2020b).

## 1.3 Social protection provisions

Entitlement and eligibility in relation to the Luxembourg LTC system are neither income- nor asset-based. Age too is not a criterion. The only requirement for entry into the system is the threshold of a minimum need of assistance in ADLs[583] of 3.5 hours per week. This need is determined by the AEC in a summary of care and assistance (*synthèse de prise en charge*). The new law defines 15 levels of care with different time allocations for their provision, varying from 210 minutes per week for level 1 to more than 2171 minutes per week for level 15.

The need for care must be regular and the status of dependency must be irreversible or last for at least six months.

The AEC may, on its own initiative or at the request of the beneficiary or LTC provider, decide to undertake a re-evaluation of dependency status, according to the deadlines laid down in the law.

[583] Activities of daily living (*actes essentiels de la vie* – AEV).

## 1.4 Supply of services[584]

The services covered by LTC insurance include assistance for: ADLs;[585] activities intended to support the independence and autonomy of the beneficiary;[586] and for technical aids (such as walkers, wheelchairs, and special beds). In addition, in the case of residential care the services covered by law include support activities in LTC facilities[587] (a flat rate of four hours per week by default, which may be increased in the event of exceptional gravity noted by the AEC to 10 hours per week). In the case of homecare, they include supervision activities[588] (a flat rate of seven hours per week for individual supervision, 40 hours per week for group supervision and 10 nights per year for night-time supervision – the first two flat rates can be increased in the event of exceptional gravity noted by the AEC to 14 and 56 hours per week, respectively). Additional benefits for homecare are: assistance with household chores (a flat rate of three hours per week);[589] incontinence equipment; home adaptations; training for technical aids (a flat rate of two hours per year); and training of the informal carer (a flat rate of six hours per year).

As indicated above, care may be provided at the home of the beneficiary, or in a residential setting. There are four categories of care-providers: (a) care and assistance networks (*réseaux d'aides et de soins* – RAS), of which there were 22 as of the end of 2019; (b) semi-inpatient facilities[590] (*centres semi-stationnaires* – CSSTA), 54 centres as of the end of 2019; (c) LTC facilities for continuous stay accommodating dependent people day and night, and providing them with all the assistance and care required for their degree of dependency (*établissements d'aides et de soins à séjour continu* – ESC), 52 centres as of the end of 2019; and (d) LTC facilities for intermittent stay[591] (*établissements d'aides et de soins à séjour intermittent* – ESI), 43 establishments as of the end of 2019.

These providers may be either public, private for-profit, or non-profit. There are no data available about the market shares of these three forms of providers: but after comparing data of the IGSS, the CNS, and, COPAS, the market shares can be approximately defined as shown in Table 1.

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[584] All figures in this subsection are drawn from IGSS (2020b).
[585] As laid down in Art. 350 of the CSS.
[586] The purpose of these activities is to learn or maintain the motor, cognitive or psychological capacities required to perform essential ADLs or to limit the worsening of dependence in relation to them. The objective of independence support activities is to teach dependent people to participate actively in carrying out ADLs by maintaining or improving motor, cognitive or psychological capacities, or at least by trying prevent a reduction in them. Independence support activities are carried out individually or in groups. They are taken into account for a weekly flat rate of five hours individually or 20 hours in a group.
[587] These support activities consist of supervision during the day for people who cannot remain alone for a long time. They are designed to guarantee the safety of dependent people, to avoid harmful social isolation, and to help structure beneficiaries' lives over time.
[588] 'Supervision activity' means that an informal carer or an employee from a care and assistance network monitors a dependent person at home, if their physical and/or mental integrity cannot be guaranteed in the absence of a carer. Supervision activities can also be provided during the night (night-time supervision).
[589] Guarding activities and household maintenance assistance activities belong to social care.
[590] These could be either daycare or night-care centres (although there are currently no night-care centres in Luxembourg).
[591] Accommodating dependent people day and night, and providing them with all the assistance and care required according to their degree of dependency, but allowing an alternation between staying in the centre and staying in a private home. This category is predominantly but not exclusively designed to meet the needs of people with disabilities.

**Table 1 – Estimated market shares of different forms of LTC providers, end-2018**

| Categories/forms of providers | Public | For-profit | Non-profit |
|---|---|---|---|
| RAS | 0.0 % | 27.3 % | 72.7 % |
| CCSTA | 13.0 % | 5.6 % | 81.4 % |
| ESC | 40.4 % | 9.6 % | 50.0 % |
| ESI | 4.7 % | 0.0 % | 95.3 % |

*Source: Own calculations using data from IGSS (2020b), CNS, and COPAS (data collected by phone).*

In 2019, 67.8 % of 14,832 beneficiaries received homecare benefits (including benefits provided in an LTC facility for intermittent stay), whereas 32.2 % of beneficiaries lived in an LTC facility for continuous care.[592]

The AEC and the beneficiary jointly decide if part or all of the care may be provided by an informal carer. If the AEC evaluates the proposed carer as able to perform the tasks required, benefits in-kind are replaced with cash benefits.[593] These are paid to the beneficiary, who may then conclude a contract with the informal carer.

The above-mentioned providers employed 9865 FTE (full-time equivalent) workers in 2019 (see IGSS, 2021), of which 72.0 % (7106) were care workers, 8.2 % (804) were socio-educational staff, 5.7 % (560) were administrative staff, and 14.1 % (1395) were technical and logistical staff. Around 6.2 % of the first two categories have no qualifications. Out of the 9050 beneficiaries cared for at home, 1166 opted for cash benefits and 5098 for a combination of cash and in-kind benefits. The evaluation of informal carers has been introduced with the reform of LTC insurance in 2018. Out of the 6264 beneficiaries living at home who relied partly or totally on an informal carer at the end of 2019, 3446 (55.0 %) relied on an informal carer who had already been evaluated by the AEC. As the quality aspects of LTC insurance impose a regular re-evaluation of LTC beneficiaries, the remaining informal carers will be evaluated in the coming years (IGSS, 2021).

Amongst the employees of the different providers, 27.9 % work for care and assistance networks, 4.5 % for semi-inpatient facilities, 56.1 % for LTC facilities for continuous care, and 11.5 % for LTC facilities for intermittent stay.

[592] Data source: Inspection générale de la sécurité sociale, *Rapport Général sur la Sécurité Sociale 2020*, Luxembourg, IGSS, 2021. Available here: https:/igss.gouvernement.lu/fr/publications/rg/2020/rg-2020.html. For international comparisons: in 2019 6.7 % of the population aged 65 and over received care at home and 5.2 % received care in an institution.

[593] The cash benefits vary between EUR 12.50 per week if the informal carer provides less than 61 minutes of care per week, and EUR 262.50 per week if they provide more than 540 minutes per week.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

The number of potentially dependent people was 55,700 in 2019. In 2019 the shares of the population aged 65 and over receiving residential care, homecare, and cash benefits were 5.2 %, 6.7 %, and 0.9 % respectively. Unmet needs for LTC were relatively small in 2016: 3.3 % for financial reasons and 0.3 % because services were not available. A recent Eurofound study reports that the *'lowest percentage (less than 35 %) of home care users finding it difficult – to a great, moderate or some extent – to afford services was found in the Nordic countries and Luxembourg*'. [594] According to an ESPN report, [595] access and availability in relation to LTC was easiest in Belgium, Cyprus, Denmark, Luxembourg, and the Netherlands.[596] However, since the number of care recipients is projected to increase, as reported in Section 1, this would require a massive expansion of LTC services, both in homecare and in residential settings. The resulting increase in public expenditure may make it more challenging for Luxembourg to continue ensuring the availability of LTC services.

The LTC system in Luxembourg can currently be assessed as adequate, as the proportion of the older population who would be at risk of poverty (AROP) after paying for the out-of-pocket costs of their homecare is around 0 % for low needs, 10 % for moderate needs, and also 10 % for severe needs. The system is also equitable, because the share of homecare costs met by public social protection systems for older people at risk of poverty is nearly 100 %, and no older people would be pushed into relative income poverty after paying for the out-of-pocket costs of homecare for low needs.[597] There is, however, a gender gap as there is a certain difference between the incomes of older men and older women, even if both incomes are higher than 180 % of the AROP threshold. Finally, the system is also efficient, as it achieves an AROP rate of 0 % for older people using homecare, while spending on LTC is 1.0 % of GDP.[598]

However, there is the minimum requirement of needing 3.5 hours of help with ADL per week (and for a minimum of six months) to enter the LTC system. People with lower or shorter needs are excluded from LTC benefits, except for palliative care, technical aid, and accommodation adaptation.

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[594] Eurofound, *Quality of Health and Care Services in the EU*, Publications Office of the European Union, Luxembourg, 2019.
[595] Pacolet, J. and De Wispelaere, F., *ESPN Thematic Report on Challenges in long-term care*, European Social Policy Network (ESPN), European Commission, Brussels, 2018.
[596] Eurofound, *Care Homes for Older Europeans: Public, for-profit and non-profit providers*, Publications Office of the European Union, Luxembourg, 2017.
[597] Cravo Oliveira Hashiguchi, T. and Llena-Nozal, A., *The Effectiveness of Social Protection for Long-term Care in Old Age: Is social protection reducing the risk of poverty associated with care needs?,* OECD Health Working Papers, No 117, Organization for Economic Co-operation and Development (OECD Publishing), Paris, 2020 (e.g. pages 30 and 48). See also footnote 25.
[598] Whereas the regression line would suggest LTC spending of more than 2 % of GDP to reach the same effect. See: *Measuring Social Protection for Long-term Care in Old Age: Final Report*, Organization for Economic Co-operation and Development (OECD), Paris, 2019.

The affordability of dependency insurance is not an issue, since it covers all costs and there are no out-of-pocket expenses for the supply of services, apart from lodging costs in the case of residential care (accommodation and services such as meals, basic domestic services, laundry). Beneficiaries who cannot afford to pay for these costs may be awarded means-tested support, called *accueil gérontologique*, from the national solidarity fund [599] which is calculated so as to guarantee pocket money for the beneficiary of EUR 475.81 per month. In 2019, 615 people benefited from this support, totalling EUR 7.9 million.[600] If necessary, adult children pay maintenance for their parents or other ancestors in need (Article 205 of the civil code).[601]

## 2.2 Quality

The Ministry of Family specifies the criteria for the accreditation and hence the authorisation that providers must have by law.[602] The regulation lists all the requirements for buildings and technical installations. A draft law recently introduced in parliament[603] is designed to clarify the criteria and hence further improve the quality of infrastructure, which may be subject to budget constraints or watered down in the future.

The AEC is entrusted by law with quality control and ensuring that the services provided match the needs of dependent people. For all care settings it evaluates the quality of the input, the result, and the process. To implement the law and the quality system described, a regulation [604] defines the required qualifications and staffing standards to guarantee input quality. A second regulation[605] defines the quality indicators used to measure the results. The future quality of the system may only be guaranteed if these quality standards are not watered down.

The quality of LTC depends on the workforce, the facilities, and the way these two are combined to deliver the expected results (i.e. the management of the LTC system).

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[599] Fonds national de solidarité – FNS.

[600] *Rapport d'Activité 2019*, Ministère de la Famille, de l'Intégration et à la Grande Région, Luxembourg, 2020.

[601] ***Art. 205.*** *Les enfants doivent des aliments à leurs parents ou autres ascendants qui sont dans le besoin.*
*La succession du conjoint prédécédé, même séparé de corps, doit des aliments au conjoint survivant, s'il est dans le besoin.*
*La pension est supportée par tous les héritiers et, en cas d'insuffisance, par tous les légataires particuliers proportionnellement à leurs émoluments.*
*Toutefois, si le défunt a déclaré que certains legs doivent être acquittés de préférence aux autres, ces legs ne contribuent à la pension que pour autant que le revenu des autres n'y suffise point.*
*Si les aliments ne sont pas prélevés en capital sur la succession, des sûretés suffisantes seront données au bénéficiaire pour assurer le paiement de la pension.*

[602] *Règlement Grand-ducal du 13 Décembre 2017*, JOGDL Mémorial A 1095 du 19 décembre 2017, Grand-Duché de Luxembourg, Luxembourg, 2017d. Nine different accreditations are listed in this regulation; each of these is based on requirements for providers regarding qualifications and staffing standards, criteria for infrastructure, documentation requirements, opening schedules, the existence of an action plan (*projet d'établissement*), etc.

[603] *Projet de loi portant sur la qualité des services pour personnes âgées et portant modification de: 1° la loi modifiée du 16 mai 1975 portant statut de la copropriété des immeubles bâtis; 2° la loi modifiée du 8 septembre 1998 réglant les relations entre l'Etat et les organismes œuvrant dans les domaines social, familial et thérapeutique*, Document parlementaire No 7524, Chambre des Députés, Luxembourg, 2020a.

[604] *Règlement grand-ducal du 13 décembre 2017, modifié par Règlement grand-ducal du 18 septembre 2018,* JOGDL Mémorial A 876 du 27 septembre 2018, Grand-Duché de Luxembourg, Luxembourg, 2017b.

[605] *Règlement grand-ducal du 13 décembre 2017*, JOGDL Mémorial A 1094 du 19 décembre 2017, Grand-Duché de Luxembourg, Luxembourg, 2017c.

With regards to the workforce, formal carers are required to go through rigorous education and training, and there are sufficient jobs in a wide range of professions stipulated in the different settings of LTC[606] (IGSS 2020b). Since a part of the workforce, not only immigrants and commuters but also (Luxembourg) residents, is trained abroad, the Luxembourg authorities only have limited influence on their training and hence the quality of the service they provide.

With respect to informal carers, the AEC is in charge of organising training for informal carers. However, an inspectorate report (IGSS, 2021) mentions that, in 2019, the summary of care for only 209 beneficiaries included training for the informal carer.

The Ministry for Social Security establishes the relevant laws for the long-term care sector. The Ministry of Health and the Ministry for Family, Integration and the Greater Region supervise the accredited providers. The providers themselves are responsible for the correct implementation of the long-term care system, bringing together human and material resources. COPAS is the representative organisation for long-term care providers, recognised as the negotiating partner with the CNS in context of the determination of the monetary value of the long-term care services. On the other hand, collective labour agreements are negotiated between COPAS and the social partners.

## 2.3 Employment (workforce and informal carers)

In 2018, the various providers of LTC employed 9641 FTE staff (equal to 10.7 per 100 people aged 65 and over). With respect to the expected beneficiaries in the future (see Subsection 1.1) 15,314 FTE staff would be needed in 2030, and 27,300 in 2050. These are increases of roughly 50 % by 2030 and 170 % by 2050. At present it is difficult to imagine where these workers might come from. Although the total population and therefore the pool of future recruits is also expected to grow, it will do so more slowly. Furthermore, the population of neighbouring regions is not expected to increase at the same pace. It is not guaranteed that Luxembourg will continue to avoid recruitment problems.[607]

The overall compensation of employees should not be an obstacle to recruitment – on the contrary, the well paid jobs in this sector are very attractive, especially for commuters from the three neighbouring countries. From 1 October 2017, a new collective agreement entered into force with salary revaluations for professional care workers. For the highest career level (C7) – employees with a master's degree – the monthly salary varies from EUR 7004.92 at the beginning of a career to EUR 10,289.71 at the end (these are gross salaries before taxes and social security contributions). For the lowest career level (C1), corresponding to an administrative or technical profession without any qualifications or diplomas, the monthly salary range over a career is EUR 2433.91 to EUR 3838.85.[608] This may be compared with

[606] *Bilan sur le Fonctionnement et la Viabilité Financière de l'Assurance Dépendance 2013*, Luxembourg, IGSS, 2013; *La Sécurité Sociale 2019: Assurance dépendance – Rapport d'analyse prévisionnel*, Luxembourg, IGSS, 2019.
[607] *Who Cares? Attracting and retaining care workers for the elderly*, OECD Health Policy Studies, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en.
[608] *Convention collective de travail pour les salariés du secteur d'aide et de soins et du secteur social (CCT SAS)*, Fédération des acteurs du secteur social au Luxembourg (Fedas), Luxembourg, 2017. http://www.fedas.lu/wp-

the minimum wage, which as of 1 January 2020 was EUR 2141.99 for workers without qualifications. It should be noted, however, that LTC workers are less well paid than those in the healthcare sector (OECD, 2020).

Jobs in the LTC sector need to be very attractive, because today's providers are already struggling to find enough resident employees and therefore recruit about 45 %[609] of their workforce from outside the country, mostly commuters from France, Belgium, and Germany.[610] With the growing demand for new recruits, even more commuters and resident recruits will have to be found, which may become increasingly difficult.

Another possible challenge with regards to the workforce is the potential decline in the number of people available to become informal carers. Informal carers, on which approximately 69 % of homecare beneficiaries rely, are in the vast majority women (see also IGSS, 2013 and 2020b). One target of the Europe 2020 strategy is to increase the employment rate. The Luxembourg government has set the target at 73 %, and the increase in recent years has mainly been due to the increase in women's employment.[611] Since younger women are increasingly taking up employment, more so than in older generations, this may lead to a lower percentage of women inclined or able to take on informal care. This would add two challenges to the LTC system in two ways. First, it would further increase the numbers of formal carers needed. Second, as informal care results in fewer expenses[612] than care provided by paid employees, a resulting shift to formal care may result in an increase in overall public LTC expenditure.

Language is another challenge with regard to the workforce. Many commuters, predominantly from Belgium and France, are employed in the Luxembourg LTC sector; but a large portion of these do not speak Luxembourgish, which causes comprehension problems with older Luxembourg beneficiaries who often are not fluent in French.

## 2.4 Financial sustainability

As underlined above, the future increase in the number of care recipients will require a massive expansion of LTC services, and so increased financial investment will be necessary in this sector. LTC spending in Luxembourg is thus projected (2021 Ageing Report[613]) to increase from 1.0 % of GDP in 2019 to 1.1 % in 2030 and 1.8 % in 2050 (according to the AWG reference scenario), compared with the EU-27 average of 1.7 %, with eight Member States having higher spending of 1.7-3.7 % of GDP.

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content/uploads/2018/01/CCT-SAS-en-vigueur-du-1er-octobre-2017-au-31décembre-2019.pdf. *Règlement Grand-ducal du 15 Mai 2018*, JOGDL Mémorial A 458 du 7 juin 2018, Grand-Duché de Luxembourg, Luxembourg, 2018a.

[609] As there are no specific figures for the LTC sector, the share of commuters reported here is for the whole healthcare sector. See: *State of Health in the EU: Luxembourg – Country health profile 2019*, OECD Publishing, Paris / European Observatory on Health Systems and Policies, Brussels, 2019.

[610] This is not specific to the LTC sector; it is the general pattern in the Luxembourg economy.

[611] *Luxembourg 2020: Plan national pour une croissance intelligente, durable et inclusive – Programme national de réforme du Grand-Duché de Luxembourg dans le cadre du semestre Européen 2019*, Gouvernement Luxembourgeois, Luxembourg, 2019.

[612] Here: direct expenses to the LTC system. Opportunity costs with regards to the labour market participation of informal carers and other hidden costs are not taken into account.

[613] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

Based on the AWG projections, the financial sustainability of the LTC system is challenged. Indeed, the 2020 country report from the European Commission stresses that, with no policy change, there would be a large impact on public debt.[614]

In addition, LTC spending Luxembourg is expected to grow more quickly according to the AWG risk scenario, from 1.0 % of GDP in 2019 to 1.3 % in 2030 and to 2.6 % in 2050.

### 2.5 Country-specific challenges regarding LTC for other age groups in need of care

For the time being, there are no challenges reported anywhere in relation to age groups other than older people.

## 3 REFORM OBJECTIVES AND TRENDS

An important reform of the LTC insurance system came into force in January 2018 (Grand-Duché de Luxembourg, 2017a). This reform, however, did not call into question the system's guiding principles of the long-term care insurance (see Subsection 1.2).

With this reform, greater flexibility was put in place with regards to ADLs: activities were standardised, allowing them to be regrouped, and flat-rate billing replaced fee-for-service billing based on a price assigned to each activity. This also allows greater flexibility in care plans allocated by the AEC. According to the explanatory statement (*exposé des motifs*) of the draft law, another goal was the development of a transparent and effective policy/control system in relation to quality.[615] The quality system is defined in terms of three levels of control: control of the quality of LTC services; the regular evaluation of the care needs of dependent people and informal carers; and finally consistency between the care needs of dependent people and the level of care defined by the AEC in the evaluation process. To implement this law and the quality system, the government issued a range of regulations (see Subsection 2.2).

There are currently no other ongoing reforms, except what is detailed in the box below, and there are no plans for any in the present legislative session.[616] The 2017 reform introduced a paragraph in the CSS, requiring the IGSS to deliver a biennial report concerning the financial situation (*rapport d'analyse prévisionnel*)[617] and the AEC to deliver a biennial report on quality.[618]

[614] *Country Report Luxembourg 2020: 2020 European semester – Assessment of progress on structural reforms, prevention and correction of macroeconomic imbalances, and results of in-depth reviews under Regulation (EU) No 1176/2011*, Commission Staff Working Document, European Commission, 2020.
[615] *Projet de Loi Portant Réforme de l'Assurance Dépendance*, Document parlementaire No 7014, Chambre des Députés, Luxembourg, 2016.
[616] *Accord de Coalition 2018-2023*, Gouvernement Luxembourgeois, Luxembourg, 2018.
[617] Art. 395bis of the social security code. The first of these reports was delivered in 2019, but it was too soon after the enactment of the reform for the report to have produced any conclusions (see IGSS, 2019).
[618] Art. 384bis of the social security code. Publication was expected at the end of 2020.

### *Planned reforms and ongoing legislative process and debates*

*On 11 February 2020, the Minister for Family and Integration tabled a draft law in parliament (Chambre des Députés, 2020a) in order to improve the quality of provision in residential care for older people.*

*Amongst others, in Art.44, the draft law defines 'clubs aktiv plus', which are social services mainly aimed at people aged 60 and over and which work for the promotion of active ageing through activities and measures adapted to people's resources.*

*The government programme 2018-2023 foresees an 'active ageing' strategy, to be developed together with all the actors in the older people's sector, which will include in particular measures that: enable a smoother transition from working life to retirement; actively promote the well-being and quality of life of older people; and extend for as long as possible their ability to live independently and participate actively in life in all areas of society. The strategy will include measures to enhance the skills of older people, promote intergenerational dialogue, and consolidate social ties between generations – for example, by mobilising older people within community networks or local volunteering, and developing intergenerational activities (Gouvernement Luxembourgeois, 2018).*

*In order to keep more people at work, the Luxembourg government tabled a draft law in April 2014, introducing a 'package of age policy measures'.*[619] *These measures require an age-management plan for each company, which will be oriented to labour demands. Indeed, a higher employment rate among older workers could alleviate the pressure on LTC financing to a certain extent. To date, the draft law is still pending in parliament and there has been no more progress since 2015.*

*Until now, the ongoing COVID-19 sanitary crisis has not yet had a lasting impact on the LTC sector, as far as legal changes are concerned. The sector was nevertheless affected in the sense that the organisation of the sector's handling of the pandemic had to be managed. On the one hand, this involved logistical efforts to ensure that the necessary protective equipment was available. It should be noted here that this was not the case from the beginning. On the other hand, new regulations had to be passed regarding the protection of the beneficiaries of homecare and especially residential care. A proscription on access to the residences for employees was only issued on 30 March 2020. On the other hand, access for relatives was closed very quickly on 13 March and only cautiously relaxed again on 6 May 2020, with a further relaxation as of 20 May. The details and the date of implementation were left to the management of individual care homes.*

*On 20 May 2020 it became known that there was an order from the health department that residents of care homes who left the home (because of a hospital stay, a doctor's visit or the like) had to be quarantined for 14 days upon return. This was particularly problematic for those residents who had to attend a hospital several times a week due to dialysis and who were therefore unable to get out of quarantine. This practice was abolished with the 20 May easing.*

*Since the average age of those who have died of COVID-19 so far is 82, it could be expected that care home residents would be among them. Of the 594 people who had died of COVID-19 by 5 February 2021, 270 came from care homes for older people.*[620]

*Between mid-April and early May 2020, both residents and employees in all residential care centres were tested for the SARS-CoV-2 virus. This general testing has been regularly repeated since then.*

[619] *Projet de loi portant introduction d'un paquet de mesures en matière de politique d'âges*, Document parlementaire No 6678, Chambre des Députés, Luxembourg, 2014.
[620] Ministry of Health, IGSS: Situation at 1 March 2021.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The figures in the 2021 Ageing Report show that wider reforms in the LTC system are still necessary. These may include not only cost containment (more cost-efficiency in the system, stricter evaluations of needs and hence lower levels of care granted,[621] reduction of benefits to the strict minimum necessary, decrease in the staff-to-patient ratio, etc.), but also a widening of the income base of dependency insurance[622] (increasing the contribution rate from income, extending the contribution obligation for all incomes, exploring other sources of revenue, etc.).

A more formal description of the role and tasks of informal carers in the law and regulations, giving them a legal status and treating their remuneration as a salary could help to improve the quality of the services provided.[623]

Furthermore, putting the emphasis on preventive activities in the healthcare system and educating the population on healthy lifestyles[624] could also have a considerable impact on future LTC needs, even if it is not their primary objective.

IT-based techniques (such as electronic assistants) could replace human resources at least in the case of a few repetitive tasks, reducing costs and providing respite for carers, if done with a sense of proportion. IT-based solutions could also help overcome some of the language barriers.

[621] As previously experienced once; see Subsection 2.1.
[622] Limiting early retirement in according with the CSR would also improve the long-term sustainability of the LTC system on the income side through higher social contributions.
[623] The LTC beneficiary gets cash benefits of EUR 25 per hour if they decide to rely (partly or totally) on an informal carer. The tasks of informal carers are then clearly defined in the summary of care and assistance established by the AEC. In the actual system, informal carers can opt to get their pension contribution paid by the LTC insurance system (if they are not already receiving any kind of remuneration on which pension contributions have to be made). LTC beneficiaries and informal carers can also opt for formal employment and an affiliation to the Centre Commun de la Sécurité Sociale, where the LTC beneficiary is then the employer and the informal carer the employee. A simplified method exists, which is also widely used in the household sector.
[624] Such as the programme GIMB *Gesond iessen Méi bewegen* [healthy eating, more moving], promoted by four different Ministries: the Ministry of Health; Ministry of Sports; Ministry of National Education, Children and Youth; and Ministry for Family, Integration and the Greater Region.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 0.5 | 0.6 | 0.7 | 0.8 |
| Old-age dependency ratio, 2019 | | 20.6 | 20.7 | 26.9 | 41.7 |
| Population 65+ (in millions), 2019 | Total | 0.1 | 0.1 | 0.1 | 0.2 |
| | Women | 0.0 | 0.0 | 0.1 | 0.1 |
| | Men | 0.0 | 0.0 | 0.1 | 0.1 |
| Share of 65+ in population (%), 2019 | | 14.0 | 14.4 | 18.1 | 25.5 |
| Share of 75+ in population (%), 2019 | | 6.5 | 6.6 | 8.1 | 13.8 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.6* | 20.9 | | |
| | Women | 21.6* | 22.4 | 23.5 | 25.4 |
| | Men | 17.3* | 19.2 | 20.1 | 22.0 |
| Healthy life years at the age of 65, 2018 | Total | 11.5* | 9.1 | | |
| | Women | 12.4* | 8.8 | | |
| | Men | 10.5* | 9.1 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 55.7 | 68.5 | 88.7 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 21.9 | 30.2 | 50.6 |
| | Women | | 14.6 | 19.4 | 32.3 |
| | Men | | 7.3 | 10.8 | 18.4 |
| Share of potential dependants in total population (%), 2019 | | | 9.0 | 9.9 | 11.5 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 24.4 | 23.7 | 25.6 |
| Share of population 65+ in need of LTC** (%), 2019* | | 16.0 | 11.6 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 5.2 | 5.0 | 6.3 |
| Share of population 65+ receiving care at home (%), 2019 | | | 6.7 | 6.5 | 7.5 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.9 | 0.9 | 1.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 49.0 | 48.4 | 53.8 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 3.7 | 3.7 | 3.8 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 66.6 | 74.6 | | |
| | Women | 68.0 | 76.3 | | |
| | Men | 64.3 | 71.7 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 9.3 | 8.5 | | |
| | Women | 9.1 | 9.9 | | |
| | Men | 9.6 | 6.7 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 3.3 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 0.3 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 1,182.8 | 1,168.0 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 7.4 | 7.9 | | |
| | % Women | | 92.2 | | |
| Share of population providing informal care (%), 2016 | Total | | 6.2 | | |
| | Women | | 7.3 | | |
| | Men | | 5.1 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 17.8 | | |
| | Women | | 21.6 | | |
| | Men | | 12.2 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.5 | 1.0 | 1.1 | 1.8 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.5 | 1.0 | 1.3 | 2.6 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 53.9 | 63.8 | 64.4 | 68.3 |
| Public spending on home care as % of total LTC public spending, 2019 | 39.3 | 35.6 | 35.0 | 31.3 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 6.8 | 0.6 | 0.6 | 0.4 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.9 | 0.9 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.2 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.1 | 0.1 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.1 | 0.1 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# HUNGARY

***Highlights***

- Cost projections show that demography alone would explain a modest increase in future spending. Improving the adequacy of the system would increase the costs to a much larger extent. This confirms the view that the main challenge of the long-term care system (LTC) is unmet needs – that is, quality of life in old age, rather than financial sustainability.
- Despite a rapid expansion of public home care services, the LTC system is still institution-centred. The share of spending on residential care of total spending on LTC is 74 % in the public sector, which is one of the highest rates in the European Union.
- Needs for LTC in old age are distributed unequally. On average, a person with a tertiary degree becomes care-dependent more than a decade later than a person of the same age who has attained lower secondary education at most.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

In the European context, the Hungarian population is not particularly old nor is it expected to become one in the future.[625] Shares of the 65+ and 75+ age groups among the total population (19.3 % and 8.1 % respectively) are at or slightly below the EU-27 average; and they are expected to stay there (growing respectively to 21.6 %, and 10.8 % by 2030, 27.7 % and 14.2 % by 2050).[626]

There are only modest regional differences in the share of the older population. At the second level of the Nomenclature of Territorial Units for Statistics (NUTS) the average absolute deviation around the national average is just 1 percentage point (p.p.) in the 65+ age group and even at the NUTS3 level the corresponding statistic is only 1.3 p.p. There seems to be a demographic discrepancy between the capital city (Budapest, where the proportion of the 65+ age group was 20.5 % in 2019) and its immediate surroundings (Pest county, 17.1 %). The lowest rate at the NUTS3 level is 16.3 % (Szabolcs-Szatmár-Bereg county in the north-east); the highest rate is 21.9 % (Békés county in the south-east).

The oldest section of the population is estimated to increase the most. The 65-74 age group is estimated to increase by 15 % between 2019 and 2050; the size of the 75-79 age group is

[625] All data used in the text come from Section 5, 'Background statistics' unless explicitly stated otherwise.
[626] Source of data on the 80+ age group: Eurostat *proj_19np* table.

expected to grow by 45 % until 2050; but the number of those aged 80 years or older is estimated to increase by 81 % over the same period.[627]

An alternative measure that takes into account the potential shift of the demarcation point between the active age and old age (Sanderson and Scherbov, 2010)[628] suggests less intensive demographic pressure.[629] Due to an improvement in mortality at older ages, the age contour (or characteristic age) of five years of remaining life expectancy is expected to grow by 4.0 years among women and 3.7 years among men over the 32 years between 2018 and 2050. The number of people with five years life expectancy would grow by 16 % over this period – from 146,000 to 169,000. This is a significant increase, but it is more modest than the growth in the size of the population aged 80 or above, which is expected to grow by more than 80 % from 428,000 to 780,000 over the same period.

## 1.2 Governance and financial arrangements

The Hungarian LTC (LTC) system is still on the way to becoming a separate field of social protection and despite important steps being made in the last few years on integration, it still has a dual structure of healthcare and social care. The two branches have their own legislation, financing mechanisms and services. They maintain parallel institutional networks in both residential care and home care. A project that was launched in 2017, to test the way in which chronic beds and beds in nursing departments of hospitals could be replaced by special care centres (*szakápolási központ*), is still in its introductory phase.

Despite a rapid extension of home care between 2008 and 2014, the LTC system is still institution-centred. The rate of spending on residential care to total spending on LTC is 72 % in the public sector, which is one of the highest rates in the EU.

Access to public healthcare in principle is based on insurance (Health Insurance Act [83/1997] on mandatory health insurance), but it is near universal. Almost every citizen holds a relevant social insurance card. Eligibility for social care is based on need (Social Act [3/1993] on the administration and provision of social protection).

How the responsibility for social care provision is divided between the government and local governments depends on the size of the community. The smallest communities, with less than 3000 inhabitants, have to provide meals-on-wheels services and home care. Communities larger than 3000 have to add day-care centres to their care portfolio and those larger than 30,000 people have to maintain a care home for older people. The responsibility of local governments in these services is to organise provision but they may apply for funding from the central budget. Institutions serving groups of communities are maintained by the government. The provision of alarm system-based home assistance is also a government responsibility.

[627] Eurostat *proj_18np* table.
[628] Sanderson, W. C. and Scherbov, S., 'Remeasuring aging', *Science*, Vol. 329, No 5997, 2010, pp. 1287-1288.
[629] The method fixes the remaining life expectancy at five years (denoted as LEXP5) and looks for the age and number of people who are characterised by such a value in future calendar years. The calculation uses the 2018 population projection of Eurostat. The limit of five years is based on the observation that on average people need assistance in daily activities during the last five years of their lives.

Total public expenditure on LTC was 0.6 % of the gross domestic product (GDP) in 2019. In both sectors, Hungary is among those in the European Union (EU) that spend the least, although the comparison on social care expenditures is limited as data is not available for many Member States. About half (53 %) of LTC-related healthcare is financed through government schemes, and about one quarter (27 %) is based on compulsory contributory health insurance. Of the rest, 14 p.p. are out-of-pocket payments by households and another 6 p.p. is financed through voluntary healthcare payment schemes. Private insurance for LTC or employer-financed programmes are not involved.

Public finances do not cover all the costs of service providers. In 2018, 37 % of the operational costs of residential care centres were covered by fees charged to clients or their families. The amount of these fees – Ft81 billion (EUR 250 million) – was the equivalent of about 0.4 % of total individual household expenditure.[630] The burden on the care recipient in other services is smaller. Only 4 % of operational costs of day-care centres are collected from visitors; the corresponding rate for home care and 'meals-on-wheels' catering (combined) is 28 %.[631]

The Labour Act allows relatives to go on unpaid leave for a maximum period of two years. This option is open to employees who provide personal care for a permanently ill relative (Labour Act 62, §131). Needs have to be confirmed by the healthcare system and the employee has to provide care themselves. There are no statistics, from government, any non-governmental organisation or the academic sector, on the frequency and average length of such leave or its cost in terms of lost income.

Familial responsibilities of children and parents are specifically mentioned in the constitution. Based on this principle, the mandate to support older parents (*szülőtartás*) was extended in 2016 by licensing third parties, such as homes for older people, to legally force adult children to support their older parents financially, e.g. by contributing to the fee for living in a care centre.

## 1.3 Social protection provisions

The services provided under healthcare are nursing care in the nursing departments of hospitals and home nursing care; the three main types of services in social care are home care (completed with 'meals-on-wheels' services and alarm-system based assistance), day-care and residential care. Home care is split into two distinct activities, provision of personal care (*személyi gondozás*) and social help (*szociális segítés*). The former mostly includes caring for personal hygiene; the latter includes tasks such as maintaining regular personal contact with the client and performing the most basic caring activities. The former requires special training, the latter does not.

Need for care is assessed through a complex process initiated by a general practitioner (GP) and carried out by an expert committee appointed by the local notary (in the case of home care) or, by the expert committee of the Budapest Governmental Office, a multifunctional

[630] CSO Yearbook of Welfare Statistics, 2018, *szocevk_2018_09 9.3*, and Eurostat *nasa_10_nf_tr* tables (2018).
[631] CSO Yearbook of Welfare Statistics, 2018, *szocevk_2018_08 8.25* table.

administrative centre (in the case of residential care). The criteria are national standards, and they are binding; but they apply to only a segment of social care, and do not apply to healthcare. Needs assessments are not regularly reviewed.

Applicants are evaluated based on 14 different activities, such as independence in daily activities (eating, dressing, personal hygiene, toilet use, continence); following therapy; moving and changing position; mental functions (orientation in space and time, communication, proper behaviour); eyesight and hearing; the need for supervision. Abilities are measured on a scale of 0–3 (0: can manage; does activities on their own; 1: needs support in some activities; 2: needs partial support; 3: needs full support). The resulting values are translated to care type and time. People at level 0 are eligible only for social help and only if they meet further conditions: either the person is older than age 65 and lives on their own; or older than age 70 and lives in a dwelling unequipped with modern water and heating services; or older than age 75 and cannot leave home due to poor health. Such additional conditions do not apply to social help if the person is categorised as level 1 or 2. Also, people in categories 1 or 2 are eligible for personal care. Residential care is only available in category 3.

Social care is financed by the government and local governments. In addition, care providers may charge user fees. The exact amount varies from service to service. Formulas for its calculation are set out in regulations, taking the user's personal income into account. Real estate assets are also part of the income calculation, but other types of assets are not. The maximum fee is 80 % of monthly income for residential care, and 50 % for rehabilitative care. In addition, providers of residential care can charge an admission fee for new users. Its maximum amount is Ft8 million (currently about EUR 22,500).[632]

At least half of the places in a residential care centre have to be free of admission fees.

The LTC system does not offer cash benefits directly for recipients. There is one type of cash benefit that supports familial care, the nursing allowance.[633] This can be claimed by relatives caring for a family member with a disability or permanently illness. Applications, based on the expert opinion of a GP, are evaluated by the local authority. The nursing allowance is aimed primarily at those caring for family members with severe disabilities or permanently illness. Depending on the health of the care recipient, an increased nursing allowance may be paid (*emelt összegű ápolási díj*), at 150 % of the standard allowance; or an extra nursing allowance can apply (*kiemelt ápolási díj*). The amount of the latter was Ft70,857 (about EUR 200) a month, 180 % of the standard nursing allowance (Ft39,365, or about EUR 110) and it can be paid to care providers if the health status of the recipient falls below the 30 % threshold on a 0 to 100 scale applied by authorities assessing health status.

The nursing allowance is not indexed, and its level is set annually by Parliament within the budget law. It is exempt from income tax. It is, however, subject to pension contributions (10 %) unless the care provider is a pensioner. The nursing allowance builds up eligibility for old-age pension (although in order for someone to participate in the 'women-40' programme,

[632] For currently effective values, April 2020 exchange rates are used throughout the report. The exchange rate of the forint to the euro is volatile.
[633] In official texts and statistics, it is alternatively called nursing fee.

a special early retirement scheme, the care recipient must be a child). The allowance is also exempt from health contributions, but recipients are covered by public healthcare.

The nursing allowance is not limited by time. It is terminated if and when the eligibility conditions cease to exist (if the health of the recipients improves, or if they die, or if the authorities find the care provider to be failing in their duties). It can be combined with four hours work per day. No such limit applies if the care provider works from home. In 2018, about 52,200 people received nursing allowance, in all forms combined.

In 2018, the government spent 0.06 % of GDP on nursing allowances. This is about 0.4 % of the entire social protection budget (excluding education but including healthcare).

In 2019, an extension was introduced to the nursing allowance called 'home nursing allowance for children.' Further details on the new benefit are presented in section 3.

## 1.4 Supply of services

In 2019, 2.8 % of the population aged 65+ received care in an institution and 2.8 % received care at home.

The importance of home care has increased over the past decade. Whereas residential capacities remained practically unchanged, the number of home care recipients grew more than 2.7 times and that of 'meals-on-wheels' services grew about 1.7 times among the 65+ age group by 2014 compared to their respective levels in 2008. In order to manage this expansion, the government cut back the per capita quota in 2013 and raised the eligibility criteria for new care recipients in 2015. This resulted in a drop in the number of recipients from 110,000 in 2014 to 84,000 in 2018 among the 65+ age group, which is still twice the number of recipients in 2008.

The main providers of social care are local governments[634] (55 % of home care; 67 % meal provision services; 70 % of day-care; and 27 % of residential care – all by the number of recipients in 2018; the rates refer to all forms of residential care irrespective of the age of the recipient); churches (40 %, 33 %, 16 % and 18 %, respectively); non-profit organisations (respectively, 2 %, 1 %, 3 % and 11 %); and central government (34 % of residential care).[635] All providers are financed through the central budget, based on the type and personnel requirements of the service; but they are expected to supplement this amount with their own resources and with the contributions of recipients.

The composition of providers of residential care changed over the last decade. In 2010, local governments operated care centres housing for about three-quarters of clients; this share decreased to about a quarter. They were replaced by the central government, which controlled no centres in 2010 (now 34 % of clients) and churches (whose share grew from 8 % to 18 %).

[634] Including associations of local governments.
[635] CSO Yearbook of Welfare Statistics, 2018, szocevk_2018_08 8.6, szocevk_2018_08 8.18, szocevk_2018_09 9.6 and szocevk_2018_09 9.9 tables.

The dominant provider of LTC in healthcare is the central government (85 % of chronic beds).[636]

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Difficulties in personal care activities or household chores can be estimated from the annual income survey of the Hungarian Central Statistical Office (CSO), which is part of the European Union Statistics on Income and Living Condition (EU-SILC) project, and the Hungarian leg of EHIS.

24.7 % of respondents aged 65 and over reported difficulties in personal care or household activities in the 2019 wave of EHIS (referred to above in section 1.4).

In 2018, a total of 328,500 people received some form of public LTC service, all types of services combined (including potential overlaps in various forms of home-based care) in the following break-down: about 84,000 in home care, 142,000 in social catering, 20,000 in alarm system-based home assistance, 32,000 in day-care and 50,500 in residential homes.[637]

The rest was taken care of by relatives or the person in need had to live without support because they could not afford it. The total costs of home care are about twice the average disposable income of an average older person if the care recipient has severe needs (41.25 hours care per week).[638] Actual out-of-pocket spending on home care represents about 40 % of the median income among older people with low (6.5 hours care per week) or moderate needs, but about 130 % in case of severe needs rendering it unaffordable for an older person receiving median income. It implies either a strong dependence on family or unmet needs.

Unit costs for both residential and home care are low in comparative European terms. In 2020, the quota for residential care is Ft 964,510 per person per year (currently about EUR 2750). The corresponding figure is Ft 25,000, some EUR 70 for social help and Ft 330,000 (about EUR 940) for personal care, also per annum.[639]

The Directorate-General for Social Affairs and Child Protection (*Szociális és Gyermekvédelmi Főigazgatóság*) publishes waiting list figures for LTC services. In December 2018, such lists were short for home care, social catering and alarm-system based home assistance (respectively, 1 %, 3 % and less than 1 % of recipients). However, the waiting list for

[636] CSO Yearbook of Health Statistics, 2018, *eustat_2018_06 6.2* table.
[637] CSO Yearbook of Welfare Statistics, 2018, szocevk_2018_08 8.26, szocevk_2018_09 9.12 and szocevk_2018_09 9.13 tables.
[638] Figures in this paragraph are derived from Cravo Oliveira Hashiguchi, T. and Llena-Nozal, A., 'The effectiveness of social protection for long-term care in old age: Is social protection reducing the risk of poverty associated with care needs?', *OECD Health Working Papers*, No. 117, OECD Publishing, Paris, 2020, Figures 1.1, 2.6 and 2.7. https://doi.org/10.1787/2592f06e-en,
[639] The algorithms, which the unit costs and quotas can be derived from, are set annually by the budget law.

residential homes revealed acute inadequacy: about 28,200 people were waiting in a sector that served 55,100 people[640] while its utilisation rate was 96 %.[641]

Needs are distributed unequally. They grow by age in all social groups. However, the age contours in the level of severity are significantly different depending on the level of education, which is a good indicator for income and labour market career, too. Among those aged 65-74 with no high-school diploma, the same proportion of people report limitations in personal care or household activities than among those who are older than 75 but hold a tertiary degree. The respective shares in the two groups at the subsequent severity levels are 35 % versus 37 % (no difficulties); 37 % versus 36 % (moderate difficulties); and 29 % versus 28 % (severe difficulties). The average age in the 65-74 age group is 69 years; and in the 75+ age group, it is 81 years. Consequently, those with a tertiary degree are likely to become dependent more than a decade later than those that have no high-school diploma.

## 2.2 Quality

There are national definitions of LTC quality provided by the responsible ministries in the form of government decrees or recommendations. Reflecting the dual structure of the LTC system, quality is defined separately regarding home nursing care (Decree 20/1996 NM on home nursing care) as well as social care (Decree 1/2000 SzCsM on tasks and conditions of the operation of social institutions providing personal care). The latter covers various services mentioned above, such as social help, personal care and special care centres. In addition, health-care-based services are further specified in the Hungarian Healthcare Standards (*Magyar Egészségügyi Ellátási Standardok*, MEES), which is maintained by the ministry responsible for healthcare, currently the Ministry of Human Capacities.

Quality of service is typically defined by inputs, such as minimal requirements on personnel (both number of employees and their qualification), physical conditions, infrastructure and equipment. For some services, procedures such as care planning are also prescribed in the decrees. Output measures such as subjective evaluation (e.g. client satisfaction) or objective indicators (e.g. frequency of decubitus or infections; or other health indicators) are not included in quality definitions and standards.

The quality frameworks are mandatory and apply to all providers irrespective of their legal background (whether they are maintained by the government, local government, charities, other not-for-profit providers, or for-profit establishments).

There is no specialised public agency monitoring the quality of service provisions. Quality control is performed by the departments on social affairs of Government Offices (*Kormányhivatal*) the main public administration centres operating on the third level of the Nomenclature of Territorial Units for Statistics (NUTS3). Protocols are based on the decrees mentioned above: civil servants of the offices visit the service providers' premises and check whether the input and procedural requirements are met.

[640] This number refers to the total number of clients of older people homes of whom 50.5 thousand is 65 years or older. Here the larger number is relevant, since the waiting lists do not distinguish among people by age.
[641] CSO Yearbook of Welfare Statistics, 2018, *szocevk_2018_09 9.1* table.

An alternative, though indirect, control mechanism is the legal framework for protecting the rights of service users and patients, respectively. These rights are personified by legal representatives of the respective social groups (respectively, *ellátottjogi* and *betegjogi képviselő*). These representatives are independent of the service provider. However, the legal framework describing the rights and the way representatives protect them, do not include specific references to the quality of services.

A further potential channel for quality feedback is the Forum of Representatives (*Érdekképviseleti Fórum*), a consultative body consisting of elected representatives of the clients of residential centres, their relatives, the employees of the centre, as well as the representative of the owner/maintainer. The Forum has consultative rights including preliminary comments on annual workplans, internal rules and policies and information leaflets released to clients. It can demand information from the management; it discusses complaints; and it can initiate action including moves against the institution at the authorities.

Registration by the assigned Government Office is a necessary operational condition for any service provider. Licences are issued based on the ability of the potential provider to meet the requirements specified by the government decrees.

Quality control does not provide positive, only negative incentives. If the Government Office finds that the provider does not meet one of the input or procedural requirements, they levy a fine based on the Social Act. The Act gives a detailed description on the fining process, leaving little discretion to the Government Office. If violations are persistent, the operating licence can be replaced by a provisional licence (where the provider has to go through a process of regaining the standard licence again). As a further step, the provider would be drawn under administrative control; and as a final measure, the licence for operation would be permanently withdrawn and the facility would be closed.

The quality of informal care, including care financed through the nursing allowance, has no official definition. No specific regulations, guidelines, protocols or other tools are developed; no checks and monitoring are offered in the informal sector of home care.

## 2.3 Employment (workforce and informal carers)

The public LTC sector employed about 35,500 nurses in 2018, 34 % in home care, 59 % in residential care and 7 % in day-care. These figures apply to the entire LTC sector including services for people below the age of 65. Over 90 % of the 12,000 nurses in home care has special qualifications for the job. An average nurse served 7.8 clients. The number of nurses in residential care was 21,000, but this number, too, included all types of residential centres, not just homes for older people. Qualification rates (91 %) were similar to those of home care; the number of clients per nurse was 4.3. Overall, there were 2.2 care workers per 100 people (65+ population) in 2016, significantly less than the EU-27 average (3.8). The care sector workforce is female-dominated: 89 % of LTC workers are women. Wages are low, even by Hungarian standards: the average net monthly wage in the social sector was slightly above Ft 116,000 in 2019 (EUR 360), or 48 % of the national average net wage, making this the least well-paid sector.

A significant part of the need for LTC has to be met by family networks. The bulk of such responsibilities falls on women. While childcare is probably a more frequent reason for women to take up part-time employment or to not seek employment at all, looking after incapacitated adults or fulfilling other caring responsibilities are also both common reasons for inactivity among women who are of an age when they no longer have small children. Among economically inactive women in the 15-39 age group (i.e. in the age group of those who have small children but not yet ailing parents), more than a third gave one of those two reasons for not looking for paid work. Among 40-59-year-olds, the rates are still 21 % and 27 %, respectively. Over age 55, the proportions are lower, mostly because these cohorts can already seek ways to retire early.[642]

The corresponding rates among men are much lower.

The public LTC sector does not provide support measures, such as training or skill validation or support for preserving the mental health for informal carers. Such activities are left to civil society.

LTC has the capacity to create tensions not only in the supply of female labour in general but also in the supply of professional care work. In the absence of systematically collected data, we have to rely on anecdotal evidence: this suggests that the local supply of carers is inadequate – not least because Hungarian care workers tend to migrate to richer Member States, particularly Austria and Germany, and the UK. While Hungary exports labour, it also imports care workers, mostly from the ethnic Hungarian communities of Romania and Ukraine.

## 2.4 Financial sustainability

Cost projections show that demography alone would explain a modest increase in future spending. Improving the adequacy of the system would increase the costs to a much larger extent. This confirms the view that the main challenge of the public LTC system is unmet needs – that is, the relief of the labour currently captured in familial care work and the quality of life in old age – rather than financial sustainability.

In the reference scenario of the 2021 Ageing Report[643] public LTC spending increases from 0.6 % of GDP in 2019 to 0.9 % in 2050. According to the risk scenario, the LTC budget would increase faster, to 2.0 % in 2050.

The net cost of relieving families of care obligations and improving the quality of life of older people is lower than the difference between current and expected future spending. This is because labour that is currently occupied in unpaid household work would enter the labour market and pay taxes.

[642] Eurostat *lfsa_igar* table (2018).
[643] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

LTC has low potential to raise public awareness or generate public debates. The issue that raised attention and gathered momentum in 2017-2018 was a new cash benefit, the 'home nursing allowance for children' that was introduced in 2019 (for further details see Section 3).

# 3 REFORM OBJECTIVES AND TRENDS

In 2017, the Ministry of Human Capacities developed the technical and financial details of establishing special care centres (*szakápolási központ*). The project aimed to establish integrated LTC services combining residential social care with limited healthcare services. The plan included reallocating existing healthcare capacities to integrated social care. However, the programme stalled and has not got beyond a pilot project so far.

The 'home nursing allowance for children' (*gyermekek otthongondozási díja* or *gyod* in short, see in Section 2.5) was introduced in 2019 for parents nursing children with disabilities or with permanent illnesses, including adult children, at home. Although a separate category under law, it is in practice the fourth type of nursing allowance complementing those discussed in Section 1.3.

The *gyod* is a first, although still limited, attempt to remunerate familial home nursing as a job. The original forms of nursing allowance did not aim to act as a market wage for a carer, nor were they meant to replace the wage of the caring family member, rather offering some limited compensation. In 2019, the net basic nursing allowance was a mere 14 % of the average net wage in the economy; 29 % of the average net wage in the social care sector, which is by far the lowest-paid sector of the economy; and 34 % of the official net minimum wage. The introduction of the increased and extra allowances was a first step in the socialisation of familial care, but even the net extra nursing allowance was only 25 % and 52 % of the average net wage in the economy and the care sector respectively, and 61 % of the net minimum wage.

Against this backdrop, the *gyod* is an important move towards the recognition of family home nursing care as an official job. Its net amount was 77 % of the average net wage in the social care sector, which the actual activities of caring for a family member should belong to, and 91 % of the net minimum wage. The government promised to raise it to the level of the minimum wage by 2022.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The public budget for LTC can finance only limited access to services and sometimes inadequate provisions. LTC is the least well-paid sector of the Hungarian labour market by far. At bottlenecks, such as residential care, there are long waiting lists. The informal care sector is left without guidance and support. The main challenge of the LTC system is unmet needs – that is, quality of life in old age. It is not population ageing that would increase the costs in the future but the provision of adequate services.

- Residential care centres were the focus of public debate during the first outbreak of the COVID-19 pandemic. The epidemic reached Hungary later than other EU countries and the authorities had more time to prepare. The total number of fatalities remained low compared to other European countries (53.8 per million people as of May 31, 2020). On May 26, the cumulative number of care home deaths was 115 or 24 % of all deaths. This figure, though lower than in several other Member States,[644] reflects the concentration of fatalities in care centres. The ensuing public debate put residential centres in the spotlight that could be mobilised to address LTC challenges.
- The dynamics of public spending on home care was associated with changes in the general conditions of the labour market. The expansion of the home care network created jobs at a time of high unemployment and especially in places where employment opportunities were scarce. As the economy recovered and maintaining growth needed workers the public expenditure on home care was cut back. Such jobs could be recovered at low cost to improve the quality of life of older people.
- A cost-effective way to extend capacities, ease access and shorten the waiting lists would be the completion of the programme on special care centres (*szakápolási központ*). The Ministry for Human Capacities have prepared detailed plans for the financial and technical operation of such centres. Also, plans exist for the reallocation of existing health care capacities for this integrated care service.

[644] https://edition.cnn.com/2020/05/26/world/elderly-care-homes-coronavirus-intl/index.html

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 10.0 | 9.8 | 9.6 | 9.3 |
| Old-age dependency ratio, 2019 | | 23.5 | 29.3 | 33.7 | 47.5 |
| Population 65+ (in millions), 2019 | Total | 1.6 | 1.9 | 2.1 | 2.6 |
| | Women | 1.0 | 1.2 | 1.3 | 1.5 |
| | Men | 0.6 | 0.7 | 0.8 | 1.1 |
| Share of 65+ in population (%), 2019 | | 16.2 | 19.3 | 21.6 | 27.7 |
| Share of 75+ in population (%), 2019 | | 7.1 | 8.1 | 10.8 | 14.2 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 16.5* | 16.9 | | |
| | Women | 18.2* | 18.6 | 20.2 | 23.0 |
| | Men | 14.1* | 14.8 | 16.4 | 19.3 |
| Healthy life years at the age of 65, 2018 | Total | 5.7* | 7.2 | | |
| | Women | 5.9* | 7.4 | | |
| | Men | 5.4* | 6.9 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 696.0 | 746.6 | 799.4 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 406.9 | 466.1 | 574.0 |
| | Women | | 279.3 | 314.7 | 364.1 |
| | Men | | 127.6 | 151.5 | 209.9 |
| Share of potential dependants in total population (%), 2019 | | | 7.1 | 7.8 | 8.6 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 21.2 | 22.4 | 22.3 |
| Share of population 65+ in need of LTC** (%), 2019* | | 33.8 | 24.7 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 2.8 | 3.1 | 3.4 |
| Share of population 65+ receiving care at home (%), 2019 | | | 2.8 | 3.0 | 3.0 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 26.2 | 27.3 | 28.8 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 44.4 | 49.0 | | |
| | Women | 41.4 | 48.4 | | |
| | Men | 53.3 | 50.7 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 10.0 | 8.2 | | |
| | Women | 12.6 | 9.0 | | |
| | Men | 5.9 | 6.9 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 27.0 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 11.2 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 844.2 | 853.3 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 2.3 | 2.2 | | |
| | % Women | | 88.9 | | |
| Share of population providing informal care (%), 2016 | Total | | 8.3 | | |
| | Women | | 9.4 | | |
| | Men | | 7.1 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 29.4 | | |
| | Women | | 34.4 | | |
| | Men | | 22.0 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.8 | 0.6 | 0.6 | 0.9 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.8 | 0.6 | 0.8 | 2.0 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 52.5 | 74.0 | 73.9 | 75.0 |
| Public spending on home care as % of total LTC public spending, 2019 | 47.5 | 26.0 | 26.1 | 25.0 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 0.0 | 0.0 | 0.0 | 0.0 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.2 | 0.2 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# MALTA

## *Highlights*

*Malta's requirement for long-term care (LTC) have been given considerable attention, especially through consistent upgrades of services since the mid-1980s, but the demands are bound to increase as a result of the increasing share of people aged 65+ in the total population.*

*Malta has a mixed system of care, involving state, church and private institutions. Staying at their home [li wieħed jibqa' jgħix id-dar], and thus remain in the community is the preferred option among the Maltese and the state has developed, and continues to develop, community services to sustain this preference.*

*Through the subsidy to people who employ a carer, the quality of care for these individuals has improved since 2018, when a two-year pilot study was concluded and the scheme was formally launched, and new work opportunities for carers have been created.*

*Future funding of LTC can be problematic because all social security benefits in Malta (i.e. health, pensions and unemployment and therefore also LTC) are partially funded through compulsory weekly 'contributions' made by all 'gainfully occupied people'*[645] *and through general taxation. There is no fund specifically for social security and all expenditure in one year is made from income in that same year. Expenditure exceeds contributions and the difference is made up through general taxation.*

*Voluntary services in the LTC sector in Malta have a very long tradition and offer a golden opportunity for growth and professionalisation through more training facilities and incentives for people to dedicate time towards LTC in the community.*

# 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)[646]

## 1.1 Demographic trends

Over the past decade, the Old-age dependency ratio increased considerably, from 19.9 % in 2008 to 27.6 % in 2019, but remains below the EU-27 average even if the gap has slightly decreased over the period (the EU-27 average grew from 25.7 % to 31.4 %). The share of the population aged 65+ in the total population increased from 13.9 % to 18.7 %. By 2030, this share is projected to increase further: the 65+ will account for 21 %; by 2050 the share will go up to 25.4 %. It should be noted that between 2008 and 2019, the total population of the country increased by almost one fifth (from 408,000 to 494,000) and it is expected to continue

[645] In Maltese legislation, the term used is 'gainfully occupied people', which is only partly equivalent in meaning to 'people in paid employment'. There are three categories a) Employed People (employed with a provider of employment or employer); b) Self-Occupied People (i.e. people engaged in any activity through which earnings exceeding EUR 910 per annum are being derived, e.g. through rents); and c) Self-employed (i.e. people who have not yet passed their 65th birthday, are ordinarily resident in Malta, and are not an employed person or a self-occupied person). Members of (a) pay Class 1 Contributions (shared equally by the individual, the employer and the state), the rest pay Class 2 Contributions (shared equally by the individual and the state). All people, whether they are in standard or non-standard jobs, whether full-time or part-time, are covered by this legislation and are obliged to pay a certain amount (contribution) every week.

[646] Unless explicitly stated otherwise, all the data used in this text comes from Section 5 'Background statistics'.

to increase rapidly[647]. This is the result, especially in recent years, of net migration. In 2018 alone the population increased by 17,102 people, an increase of 17 % when compared to the previous year.[648]

Life expectancy at the age of 65 was 21.1 years in 2019 (men 19.4; women 22.5), an increase of just under two years since 2008.

The pressure on LTC provision, as measured by the share of potential dependants in the total population, is set to increase from 3.2 % in 2019 to 3.8 % in 2030 and 4.6 % in 2050.

## 1.2 Governance and financial arrangements

In view of Malta's size, all the major administrative tasks are managed centrally, by the Ministry for Senior Citizens and Active Ageing. Local Councils, of which there is one in every town and village, act as a point of contact for services. Some of them provide services like a day centre, respite care services, night shelter services and cultural activities like outings for older people.

All Maltese have a legal right to LTC if they need it, and there is no distinction on the basis of creed, income, race or any other factor. People in LTC in Malta can be broadly grouped in four categories:

- People who continue to live in their homes, supported by services;
- People who live in privately run institutions for older people;
- People who live in church run institutions (which are also private) for the older people; and
- People who live in state-run institutions.

In a number of instances, the state 'hires' beds in privately run institutions to accommodate older people. These beds are financed in the same way as beds in homes for the older people directly run by the state.

In Malta, older people have traditionally preferred to stay at home with their families if possible, and only those who could not do so move to a residential home. The state promotes this preference by providing a number of services and even finances part of the cost of having a member of one's family act as a carer, or the cost of an outsider recruited for this purpose on a full-time or part-time basis. In recent years, the number of privately-owned homes for older people have increased. In parallel, in recent years, many older people who cannot continue to live with their next of kin and prefer not to move in to a home are employing a carer.

[647] This prediction is related to the fact that many non-Maltese were settling in Malta at a time when the economy was thriving prior to the COVID-19 pandemic. These predictions might not be realised if the economy does not pick up, or if a recession hits the economy hard.
[648] See NSO News Release 108/2019. 10 July 2019. https://nso.gov.mt/en/News_Releases/View_by_Unit/Unit_C5/Population_and_Migration_Statistics/Documents/2019/News2019_108.pdf.

In Malta, children do not have a strict legal obligation to look after their older parents, although the moral obligation to do so to one's best ability is universally felt and generally followed. This results in a high incidence of informal care.

***Spending patterns***

Public expenditure on LTC in 2019 was 1.1 % of GDP. Public spending on these 'home care' services amounted to 7.2 % of total of LTC public spending in 2019, and is expected to decrease very slightly - to 7.1 % in 2030 and 6.6 % in 2050. In contrast, the proportion of public spending on residential care as a percentage of total LTC public spending is projected to increase: it amounted to 72.8 % in 2019 and is expected to be 76.9 % in 2030 and 82.2 % in 2050.

The cost of maintaining the state-run homes for older people is financed through general taxation collected nationally[649]. Residents in state-run homes for older people contribute 80 % of their pension and 60 % of their remaining net income provided that residents are left with a set minimum amount at their disposal. It is to be emphasised that the amount collected from the residents covers only part of the government expenditure to run these homes. Similarly, older people who are resident in a church or private home for older people have 60 % withheld from their pensions.

As from 2019, older people who release their state-owned private residence when they move into residential care, be it private or state, or any type of care home, and who would be willing to give up their social housing voluntarily, would have 20 % less deducted from their pensions.

Malta does not have a specific insurance fund to cater for LTC expenses. Malta's social security system is based on contributions made by all people in gainful employment during their working life, which is meant to cover them for unemployment, social security and health care requirements. All the money collected from these contributions is paid into one fund, known as the Consolidated Fund, to which all government revenue is credited, and in turn from which all government expenditure is paid.

There are no regions in Malta and thus there are no regional differences in the way LTC is managed in the country.

## 1.1 Social protection provisions

All Maltese senior citizens are entitled to state-run or state financed long-term residential care if they cannot continue to live at home. The following are eligible:

- A senior citizen over 60 years of age; or
- A person suffering from some form of disability; or
- A senior citizen who suffers from dementia; or
- A senior citizen who needs LTC; or

[649] Local Councils do not have any right to collect taxes in Malta. All taxes are collected nationally.

- A senior citizen who cannot live in their own home environment.

If a person decides to seek care in a privately-run home, they must finance themselves completely. As already indicated, people opting to stay at home are entitled to financial support.[650]

The needs for LTC are first assessed by an Assessment Team. Clients can self-refer through a telephone call or via e-mail, or can be referred by professionals or relatives. Communication is then held for an assessment by a multi-disciplinary team made up of medical doctors, nurses, therapists and social workers. In cases in which the applicant is unable to leave their house because of illness or injury, an assessment will be scheduled at their house. The assessment determines the level of services needed by the applicant and the priority level. During the assessment, advice on necessary services available within the community is also given.

In drawing up its recommendations report, the team focuses on these aspects:

- details about social and clinical (i.e. good health condition of the person) well-being;
- difficulties arising from cognitive impairment;
- mobility and dependency levels;
- availability of support.

The follow-up is then routinely organised. If a particular service is no longer necessary, the official providing it will refer and stop it. Social workers are particularly active in monitoring this.

In Malta, the vast majority of carers who opt to look after their older dependent relatives requiring LTC do not receive compensation and they have to find a way how to finance themselves. The only exceptions for this would be single or widowed citizens who might be eligible for a carer's pension or for carer's social assistance. In both cases, the carer must satisfy both a stringent capital and income means test. This is now available if the older person is indexed up to 4 on the Barthel Index[651].

It is important to note that in Malta, people employed in the public sector/public administration are in an advantageous position in view of the family-friendly measures[652] that

[650] The beneficiary will receive up to a maximum of EUR 5291 per year, from when the application is approved. See https://activeageing.gov.mt/Elderly-and-Community %20Care-Services-Information/Documents/INF %20-_%20CarerAtHomeSchemeEN.pdf.

[651] This index is internationally used to assess functional independence. For details see https://www.mdcalc.com/barthel-index-activities-daily-living-adl.

[652] See Manual of Work-Life Balance Measures for public servants at: https://publicservice.gov.mt/en/Documents/Public %20Service %20Management %20Code/PSMC %20Manuals/Manual_on_Work-Life_Balance_Measures.pdf.
The measures are divided into three groups:
a) *Paid leave for family reasons approved by directors:* marriage/civil union leave; release to attend ante-natal examinations; maternity leave and breastfeeding facilities; paternity leave; leave for medically assisted procreation; adoption leave; bereavement leave; urgent family leave; donation of vacation; leave/time-off-in-lieu (toil) for humanitarian reasons;
b) *Unpaid leave for family reasons approved by directors:* leave to accompany spouse/partner in a civil union on government-sponsored courses or assignments; parental leave (applicable to parents, legal guardians and foster carers); career break; responsibility leave; leave for a special reason;
c) *Other measures for work-life balance work on reduced hours:* teleworking; flexi-time.

are open to them but which are denied to workers in the private sector. Although these measures are not specifically intended to assist carers with dependants requiring LTC, they are *de facto* available to be used in such circumstances.

In-kind benefits provided to people in LTC who continue to live at home are provided directly by the state through CommCare[653]. *Domiciliary Nursing/Caring* is CommCare's gatekeeper for home-care nursing services and regulates what services are provided to individual applicants, as authorised by the Active Ageing and Community Care.

### 1.2 Supply of services

The range of services provided to older people who continue to live at home include the *Home-Help [Servizz ta' Għajnuna d-Dar]* system, through which an older person or an older couple have a carer assigned to them, at a small charge for a number of hours agreed between the carer and the person or couple in need.[654] Although it started as a service which provided both light domestic chores and shopping and social care support when introduced in the late 1980s, it is now restricted to light domestic chores and shopping only. Other services include:

- *A special telephone service* (known as *Telecare Plus*), which alerts a central office in case of an emergency.
- *Community Geriatrician Services*, which carry out domiciliary medical visits upon referral.
- *Respite service* available for families who take care of their older relatives at home.
- *Dementia Activity Centres*, which is a day care service for persons with dementia, it helps reduce stress for the caregiver whilst providing therapy that helps people with dementia to stay active.
- *Meals on Wheels service*, which provides a meal a day to older people and others who are still living in their own home but are unable to prepare a decent meal.
- *Night Shelters*, which are available in a limited number of localities for older adults who live alone and who, for various reasons, may feel insecure.
- *Continence service*, which offer free or subsidised incontinence pads.
- Telephone Rent Rebate for people in need of LTC;
- *Handyman Service*, which offers a range of repair jobs that vary from electrical repairs to plumbing, carpentry etc.
- *Active Ageing Centres*[655], which offer opportunities for older adults to remain physically, mentally and socially active. Each centre offers a varied programme of activities which include talks, outings, a variety of games and lifelong learning programmes.

[653] The CommCare Unit is part of the Ministry for Health. It provides health and social services to citizens who require care inside their own home, with the unit coordinating visits by nurses, physiotherapists, speech therapists, social workers and others.
[654] The charge is EUR 2.33 for a single person and EUR 3.49 for a household with more than one person. This is the amount charged per week, irrespective of the number of hours of service provided. Source: Personal Communication for Home Help administrator.
[655] There are 21 such centres spread all over Malta. In addition, the Active Ageing and Community Care also set up six other Active Ageing Centres with a totally new concept. These Centres are being run in collaboration with Local Councils and

- *Social Work* service, which provides psychological support, guidance and assistance.

Most of these services are free to all people who qualify through a means test for the 'pink form'[656], but charges to other beneficiaries are minimal.[657]

***Coverage of services***

According to EU-27 data (Section 5), the share of the population aged 65+ receiving care in an institution in 2019 was 3.9 %; the share of those receiving care at home in the same year was 7.0 %. The share of the 65+ population who used home care services for personal needs in the 12 months preceding 2019 amounted to 10.4 %.

***Size and composition of the workforce***

The number of LTC workers per 100 individuals aged 65+ in Malta has declined from 4.4 in 2011 to 3.7 in 2016 (EU-27 average: 4.2 and 3.8, respectively). Of the 2016 workforce, 85.1 % were women (EU-27: 90.8 %). As shown in Section 5, the share of the population providing informal care to dependants (*kura informali lil tal-familja*) amounted to 9.2 % in 2016 (6.8 % men and 11.7 % women); the EU-27 average was 10.3 % (men 8.6 % and women 11.7 %).

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Malta has a longstanding tradition that provides a wide range of services to cater for LTC, but despite this, demand has consistently exceeded supply. In December 2017 there were just under 2000 people waiting for a place at a home for older people. This relatively large waiting list persists despite the fact that in January 2018, the state was buying over 1000 beds from the private sector.[658] By 2020, the number of beds contracted from the private sector is calculated to add up to about 3000, using various models. In one state-run complex for older people, known as S*aint Vincent de Paul*[659], medical services are available on site. But the access challenges are still serious.[660]

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other entities, and focus mainly on lifelong learning. There are two of these centres in Malta and two in Gozo. See https://activeageing.gov.mt/en/Pages/Elderly %20Services %20Catalogue/Active-Ageing-Centres.aspx.

[656] A person qualifies for the 'pink form', which entitles them to free medicines, if they satisfy the conditions of a means test. For details, see https://socialsecurity.gov.mt/en/Documents/INF %20- %20FreeMedicalAidEN.pdf.

[657] Meals On Wheels, Night Shelters, Continence – Scheme B, Active Ageing Centres are provided at a minimal fee. Social Work service is given free of charge even if people do not have a pink form.

[658] Vassallo, M., *ESPN Thematic Report on Challenges in long-term care: Malta,* European Social Policy Network (ESPN), European Commission, Brussels, 2018. https://ec.europa.eu/social/BlobServlet?docId=19860 and langId=en.

[659] Despite the fact that this is the largest and probably the oldest residential complex housing older people (with over 1500 resident in 2018), the Social Care Standards Authority (SCSA), does not currently list it as a residential facility for older people and in April stated that 'It is to be noted that St. Vincent de Paul is currently in the process of obtaining licences by SCSA'. Private Communication from SCSA, April 2020.

[660] St Vincent de Paul has always been licensed as a nursing facility by the Health Standards Authority. However, as from October 2019, following enacting of current legislations under the Social Care Standards Authority, St Vincent de Paul Long-term Care facility, is now being licensed as a facility offering high dependency chronic care services.

According to EU-SILC data[661], 26.7 % of the population aged 65+ is at risk of poverty or social exclusion, a proportion significantly higher than the EU-27 average (18.6 %).[662]

Access is complicated by the fact that the decision to move to LTC is very often an urgent decision based on a sudden decline in health, cognition or function. This often blurs the extent to which the older themselves are free to exercise their right of choice, and in this regard appropriate support services need to be developed to ensure that the rights of the older person at this critical juncture in their lives are respected and they maintain their dignity.

As such, there are three very distinct challenges related to access and adequacy in Malta in the field of LTC:

- State provisions do not meet demand[663];
- Private provision is also not meeting demand both in terms of places (in respect of church-run homes) and cost (in respect of purely privately run homes)[664];
- Despite the services provided by the Maltese state in its 'community based services' programme, and the recent (2018) introduction of the substantial subsidy when an outside carer is employed[665], the amount required to cover the initial costs involved in recruiting a full-time carer who is not a Maltese national (which includes securing all the paperwork[666]) and those on minimum pensions cannot afford the balance payable after the subsidy.

In effect, the measures undertaken by the Maltese government to entice more older people to remain in the community and receive home care services as required by their individual needs, rather than to seek residential care, were also meant to alleviate the overall cost. This matched the culture, and therefore no alternative to these measures that help older people to continue to live in their homes and the community they know exists. In effect, residential care in the traditionally established homes for older people still carries a social stigma which the

[661] See Eurostat ilc_peps01.
[662] However, there has been increased efforts to reduce the risk of poverty for those aged 65 and over (Eurostat, 2014), by means of revised pensions and additional benefits to vulnerable older people. In fact, a decline in difficulties for older households 'in making ends meet' (n=3.4 % in 2019) has been registered (Eurostat, 2020)
[663] However, for the 2020 recurrent expenditure on residential care, the Government of Malta increased the expenditure by another EUR 25 million. This means that more beds shall be available for highly dependent older people requiring institutional long-term care. For instance, at St Vincent de Paul Long-term Care Facility a new 500 beds extension and further beds-increasing refurbishments have just been completed and currently highly dependent older people are being admitted from the community or transferred from acute or rehabilitation hospitals. This means that the needs of older people on the waiting lists to be transferred to St Vincent de Paul, on the Category 1 list (high dependency) are being adequately met.
[664] The cost varies from home to home, the daily rates for an independent to a fully dependent person fees range between EUR 45 and EUR 65 in a shared room and EUR 60 and EUR 80 in a single room depending on Full Barthel Score assessment. In one of the homes contacted, daily rates for a resident whose level of care is semi-dependent (C) is EUR 55 in a shared room and EUR 70 in a single room. The rates comprise accommodation, linen, meals and 24 hr nursing service depending on the level of care. In another home, the cost for a semi-dependent person sharing a room varies from EUR 85 to EUR 95 per day. The daily rate for a fully dependent person in a shared room is EUR 120. The supplement for a single room is EUR 50. Medical services are not included in either of these two homes. As explained elsewhere, the cost of LTC in a state or church home is only a percentage of a person's pension entitlement. By way of comparison, in 2018 the average equivalised income of people aged 65+ in Malta was EUR 940 per month according to EU-SILC data (Eurostat, ilc_di03).
[665] The government subsidy is EUR 433 per month.
[666] Most carers are non-Maltese citizens (they are often Filipinos).

average Maltese would do their utmost to steer away from as long as possible. The only exceptions where this stigma does not exist are the newly developed wealthy institutions which only the very rich can afford[667].

## 2.2 Quality

Empirical studies on the quality of LTC, in whatever format, are non-existent in Malta however, an internal study [668]carried out by the Active Ageing and Community Care in November 2020 found that a 97% satisfaction rate of the service provided amongst clients.

But a rare initiative was taken in 2015 by the National Audit Office (NAO)[669] to examine LTC structures and services in Malta. The study noted that even in those cases where the state is buying services from private homes, at the time, standards fell below acceptable adequacy levels. Among other things, the report noted that despite the millions in taxpayers' money paid to finance beds for long-term and high dependency patients in private homes, minimum nursing and caring times had fallen well short of contractual obligations. It was then noted that chronic understaffing and a lack of rigorous enforcement, sometimes even flouting of contractual obligations, resulted in grievous shortfalls.[670] The NAO report claimed that the shortfall in caring and nursing time meant that some highly dependent patients were not even receiving the necessary care they needed, despite clear contractual obligations.

The NAO study suggests that for some time quality has not been uniform in the provision of services. Since then, significant efforts have been made by the government to improve the quality of care provided in state run institutions[671]. Quality has been improved through the implementation of the Standards of Care Quality Charter in 2017. Extensive investment has been made to upgrade facilities, and to train staff. However, there is no updated study that proves that quality is always ensured. Concurrently, at the higher end of the spectrum, some privately run homes offer hotel like facilities to their clients. However, the average Maltese is unlikely to be able to afford that level of care, and therefore the question whether the average Maltese can have access to adequate LTC stands.

Likewise, the cost of privately employing a carer on a full-time basis at standard minimum statutory work conditions is higher than the maximum National Insurance pension.[672] With

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[667] The reference here is to some very recent initiatives by property developers to invest in high-end residential care services for older people. An example of which is the Hilltop Gardens by AX Care. See https://hilltopgardens.com.mt/the-lifestyle/ and, to a somewhat lesser extent, Golden Care. See https://www.goldencare.com.mt/.

[668] *Auditing the domiciliary nursing and caring service in the community,* Dr. Vincent Marmarà Ph.D.(Stir.) Sagalytics, Final Report, November 2020

[669] NAO, *Performance Audit Provision of residential long-term care (LTC) for older people through contractual arrangements with the private sector*, 2015. http://nao.gov.mt//loadfile/f833d410-39c8-4996-95db-a8c98b2c248d. Accessed on 21 January 2018.

[670] The NAO study reports that Mellieħa home was found to have given over 80 hours less caring time during three inspections in 2013 and 2014; the Żejtun home fell short by 178-202 hours; Roseville home fell short by some 40 hours; and Casa Leone fell short by 35 hours on average. The report noted that the negative variance in the provision of caring services in specific homes was generally at the same level during three points in time over a period of approximately nine months.

[671] The introduction of standards of care through the document 'National Minimum Standards for Care Homes for Older People' applies to facilities providing residential care. See https://activeageing.gov.mt/en/Documents/NMS_ENG.pdf, p. 8.

[672] Carers are employed privately, and therefore their work contract is a private one. It is however known that their conditions are more or less standard. They enjoy a fixed wage, mostly at the level of or higher than the minimum wage, plus additional benefits (like a fully-paid trip home every two years, as most carers are non-Maltese citizens). They pay social security contributions like all other employees. They live with their care recipient but pay no rent or anything for their board. The

the Carer Subsidy described earlier, these costs have been mitigated, but they still remain far beyond the reach of many. This effectively means that the best quality service (universally perceived in Malta as having a full-time home carer) is not affordable except for those who either have additional capital, or have a wealthy enough family able to support it. There are no formal standards that ensure informal care.

## 2.3 Employment (workforce and informal carers)

The number of LTC workers per 100 individuals aged 65+ in Malta has declined from 4.4 in 2011 to 3.7 in 2016 (quite similar to the EU-27 average: 4.2 and 3.8, respectively). Of the 2016 workforce, 85.1 % were women. The share of the population providing informal care amounted to 9.2 % in 2016 (EU-27 average: 10.3 %), again with quite strong gender differences: 6.8 % for men as opposed to11.7 % for women. Informal care is very extensive in Malta: in 2016, as many as 35.8 % of the informal carers reported to be providing more than 20 hours of care per week (as opposed to only 22.2 % at EU-27 level); here, the proportion of men is slightly higher than that of women (37.6 % vs. 34.7 %).

As noted above, the vast majority of carers who opt to look after their older dependent relatives requiring LTC have to find a way how to finance themselves, and stringent means tests apply for eligibility for a carer's pension or for carer's social assistance.

As also noted above, in Malta people employed in the public sector/administration are in an advantageous position due to the set of family friendly measures that are open to them (such as time-off, reduced working hours, tele-work and extended leave), but which are denied to workers in the private sector. The exact level of take-up, specifically related to LTC, is not available since the government unit that collects the data centrally does not differentiate the uptake according to the reason why the worker is doing so.

The decreasing availability of intra-family care is directly related to the expansion in the number of women in gainful employment in various sectors of the economy. This, together with dwindling family size, and the increased mobility of young couples, is creating a lot of pressure on 'who' is to provide LTC for older parents. Eurostat data[673] groups together two reasons why women either do not seek employment or why they seek only part-time employment (looking after children and looking after incapacitated adults). The share of women not seeking employment due to caring responsibilities is declining considerably (from 41.2 % in 2007 to 31 % in 2018, even though a lower figure of 23 % was recorded for 2016). In respect of those seeking only part-time employment, figures for women fluctuate around 20 % during the period 2009-2018.

Those doing voluntary or informal work in LTC have few opportunities to up-skill their work or to have their skills and experience formally recognised in order to assist them in becoming LTC professionals. In 2017, a specialised course for anybody interested to apply, inclusive of theory and practice in the care of older people was offered through the University of Malta.

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formal working hours are the standard 40-hour per week but casual assistance outside these working hours (e.g. administration of medication) is normally provided. They also have a day off per week. Information provided in a personal communication by a manager of a private agency that recruits non-Maltese nationals for this service.

[673] See Eurostat lfsa_igar and lfsa_epgar.

The following courses are also offered by CareMalta's training academy for a fee: Level 3 'Award in Healthcare'; Level 4 'Award in Mental Health Support and Care' and Level 4 'Award in Supporting Individuals with Disabilities'.

Despite these new training opportunities, the employment opportunities for caring are effectively open to non-Maltese since young Maltese women seek more lucrative jobs and follow more attractive career routes. This is also due to the fact that people working in this sector are generally paid standard wages at the lower end of salaries paid in Malta, close to the minimum wage.

## 2.4 Financial sustainability

With Malta's ageing population, the sustainability of LTC is certainly a major concern for policy makers. In 2019, one-fifth of Malta's population (18.7 %) was aged 65+.

According to the 2021 Ageing Report[674] (see projections shown in Section 5), public spending on LTC is expected to increase substantially from the 2019 figure of 1.1 % of GDP, eventually reaching 1.5 % of GDP in 2030 and 2.0 % of GDP in 2050 (reference scenario). The public spending on residential care as a percentage of total LTC public spending is expected to increase from the current 72.8 % to 76.9 % in 2030 and then to a 82.2 % in 2050. At the same time, under the Ageing Working Group risk scenario (capturing the impact of non-demographic drivers costs in LTC), public expenditure would rise even more rapidly and reach 2.8 % of GDP by 2050.

There are no ad hoc insurance funds for any aspect of social security (including LTC) in Malta and if this increase in expenditure materialises, it will have to be offset either from general taxation or through an increase in the compulsory weekly contributions to social security made by the population in gainful employment.[675]

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Besides the older people, LTC care in Malta caters for three other groups:

- children;
- people with disabilities; and
- mental health patients.

In the first two cases, LTC is provided by church-run institutions which have partnership agreements with the state. In the case of the third group, the state has full responsibility for LTC.

[674] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

[675] Despite COVID-19, the Maltese economy has held up well over the past few years and economic growth continued at a strong pace. According to European Commission Country Report 2019, Malta's GDP growth in 2018 is estimated at 6.2 %, based on strong domestic demand and, in particular, both private and public consumption. The effects of the pandemic are expected to lower it by -2.8 % in comparison to the average EU contraction of -7.5 %, thus being the lowest amongst the EU-28.

In respect of people with disabilities, the main challenges are also related to the need to strengthen current partnership to support the enormous voluntary efforts in place. State partnership in this segment is required to ensure both the provision of specialised services (like occupational therapy, physiotherapy and medical care) to people in LTC, but also to assist the voluntary sector to move residents into small units in the community, where support services of all kinds are required. The initiatives undertaken so far by *Id-Dar Tal-Providenza* (the main church institution in this sector) have been successful but more work in this area is required.

In respect of mental health patients, serious challenges exist to support initiatives to move more individuals into the community and to provide a better environment for those who require LTC than the one in which this is being currently provided at Mount Carmel hospital. This is work in progress and a white paper published in 2019 has launched initiatives for a new strategy that will hopefully bring about much needed reforms in this sector.[676]

# 3 REFORM OBJECTIVES AND TRENDS

Since 2017, no major reforms have been undertaken in the field of LTC. The last few years have been primarily years of consolidation of the reforms which had been started in the second half of the 1980s to ensure that the quality of care is improved. As such, in many instances referred to below, media campaigns intended to attract more support for the reforms and take-up in support of existing provisions and initiatives took place, rather than the introduction of new reforms as such.

**Access and affordability**

Access to residential care is being improved through the physical expansion of new facilities and services, particularly at St Vincent de Paul Residence, where a major extension, is currently under construction. The extension was approved in 2019 and will provide facilities for an additional 490 residents.

Access to homecare has also been improved in 2020 with the addition by CommCare, the government agency, of a phlebotomy service to LTC people who remain in the community.

**Quality**

Since 2017, quality has been improved through the implementation of the Standards of Care Quality Charter.

[676] See Malta Government, *Building Resilience Transforming Services: A Mental Health Strategy for Malta 2020-2030*, July 2019. https://deputyprimeminister.gov.mt/en/Documents/National-Health-Strategies/Mental_Health_Strategy_EN.pdf. Professionals working with persons with mental problems, especially at Mount Carmel Hospital, have consistently expressed their views that the hospital buildings do not facilitate the implementation of modern care facilities. The need to de-stigmatise mental care and to provide community based services in mental health are very serious challenges in Malta. See Galea, S. and Mifsud, J., 'The mental health care system in Malta', *International Psychiatry* 1, 2004, pp. 11-13 and especially Times of Malta editorial, 'Mental healthcare in crisis', 26 April 2019. https://timesofmalta.com/articles/view/mental-healthcare-in-crisis.708240 and Vassallo, R., 'Mental health: the 'Cinderella' of medicine: Taylor-East, S and Camilleri N', *Malta Today*, 25 November 2019. https://www.maltatoday.com.mt/news/interview/91188/mental_health_the_cinderella_of_medicine__sasha_tayloreast_and_nigel_camilleri#.XqcUkGgzY2x

Quality has also been improved through the formal training facilities that have been developed. Both the University of Malta, the Malta College of Science and Technology (MCAST) have launched a varied programme of certified training for potential carers.

**Making employment more attractive.**

The new opportunities for training at tertiary level referred to above, as well as the short courses provided by the CareMalta Academy are giving more respectability to the new caring professions and therefore might attract more people to take up employment in this area. This is, of course, an on-going process and only time will tell whether current initiatives to attract young Maltese will succeed.

The financial support given for employing a carer is making employment in this sector more attractive to both locals and non-Maltese workers. However, no data exists as to how many jobs have been specifically created in this sector over the last few years. Neither are there figures about how many, if any, Maltese are taking up these jobs. Percentages relative to the total population living in Malta are not indicative because of the recent rapid growth in the total population.

**COVID-19**

It was widely stated that older people and those with underlying morbidities were to be considered 'vulnerable people' as a result of the COVID-19 pandemic. In Malta, older people were advised to limit outdoor activities to a minimum. Carers who were looking after older people at home were also advised to take drastic precautions, mainly by staying in with them. Many family members caring for older people in their household were allowed to work from home and encouraged to have supplies provided by friends or other relatives.

At the national level, an effort to deliver medicines, meals and supplies to older people was made through a number of initiatives.[677] The Church actively encouraged all Maltese to act in solidarity with the most vulnerable people during the pandemic.[678]

In the meantime, visits to older people in residential care have been very severely restricted. Hospitals curtailed visits. All non-urgent procedures in hospitals and out-patient services were suspended, thus denying standard treatments older people would have received under normal circumstances.

***Planned reforms and on-going legislative process[679] and debates***

*The implementation of A Mental Health Strategy for Malta 2020-2030, aims to reach the following*

[677] See https://www.maltatogether.com/community-initiatives for a list of initiatives. The food related initiatives taken by private organisations on a wide scale are listed here. Accessed on 18 May 2020.
[678] Archdiocese of Malta (26 March 2020) 'Coronavirus pandemic: a call to solidarity with the most vulnerable'. Accessed at: https://church.mt/coronavirus-pandemic-a-call-to-solidarity-with-the-most-vulnerable/ Accessed on 18 May 2020.
[679] Previously adopted strategies include a National Strategic Policy for Active Ageing. https://family.gov.mt/en/Documents/Active %20Ageing %20Policy %20- %20EN.pdf and a national strategy for dementia in the Maltese islands. https://activeageing.gov.mt/en/Documents/book_english_book.pdf.
Furthermore, a new law was enacted in October 2019 on the application for licensing as a service provider of regulated activities under chapter 582 – Social Care Standards Authority - high dependency chronic care services - social welfare services.

*objectives, among others:*

- *To improve the mental well-being of the population by supporting individuals throughout the course of their lives;*
- *To plan services that address the whole spectrum of needs including prevention, curative, rehabilitation, reintegration and LTC.*

*This vision will be implemented through a series of actions which include:*

- *Transforming the framework within which mental health services are delivered;*
- *Building capacity and fostering innovation to improve the performance of our mental health services.*[680]

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The infrastructure for the provision of LTC services in Malta was significantly updated in the late 1980s and has been continuously adapted ever since. No significant structural changes have been made since 2017, but a number of opportunities exist for its continuous improvement. The main areas where challenges exist are:

- *Access:* Institutional services need to be expanded to meet demand. In order to meet the latent demand for home-based LTC, ancillary incentives (e.g. fiscal measures for informal carers) are necessary. Similarly, the adoption of modern technology (such as video-surveillance) could be used to provide more security to beneficiaries. It must also be ensured that LTC for those with mental illnesses is radically improved and de-stigmatised.
- *Affordability:* More financial support is required for people who cannot afford to pay for a personal carer at home. The stringent means test currently applicable for family members who are caring for a relative need to be relaxed heavily.
- *Quality:* Increased professional training opportunities to expand the workforce and to attract locals to take up the newly created jobs, rather than having to depend on imported labour, are necessary. More training opportunities need to be offered also to informal carers to improve their chances of returning to the formal labour market after stints away from paid work because of LTC needs in their family.
- *Sustainability:* Volunteering needs to be encouraged more, as they can support LTC professionals in tasks where no specialised knowledge is needed. Volunteers already organised in groups, like the church-run *Diakonia*, ought to be incorporated into official programmes of care at local level. Young Maltese need to be encouraged to opt for better insurance coverage for eventual LTC, since government pensions may not be able to cover all their requirements when they eventually need them.

Prior to the COVID-19 pandemic, Malta's booming economy was able to continue to provide the level of LTC described above, and to introduce gradual improvements as well. Whether this will continue to be possible, especially after the economic downturn as a result of the pandemic, is not clear.

[680] See Malta Government, *Building Resilience Transforming Services A Mental Health Strategy for Malta 2020-2030*, 2019. https://deputyprimeminister.gov.mt/en/Documents/National-Health-Strategies/Mental_Health_Strategy_EN.pdf

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 0.4 | 0.5 | 0.6 | 0.7 |
| Old-age dependency ratio, 2019 | | 19.9 | 27.6 | 31.9 | 40.2 |
| Population 65+ (in millions), 2019 | Total | 0.1 | 0.1 | 0.1 | 0.2 |
| | Women | 0.0 | 0.1 | 0.1 | 0.1 |
| | Men | 0.0 | 0.0 | 0.1 | 0.1 |
| Share of 65+ in population (%), 2019 | | 13.9 | 18.7 | 21.0 | 25.4 |
| Share of 75+ in population (%), 2019 | | 6.0 | 7.1 | 10.6 | 13.0 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.9* | 21.1 | | |
| | Women | 21.1* | 22.5 | 23.4 | 25.3 |
| | Men | 18.5* | 19.4 | 20.5 | 22.3 |
| Healthy life years at the age of 65, 2018 | Total | 11.9* | 14.3 | | |
| | Women | 11.7* | 14.5 | | |
| | Men | 12* | 14.0 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 15.9 | 22.3 | 30.6 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 9.8 | 15.0 | 22.3 |
| | Women | | 6.5 | 9.5 | 13.4 |
| | Men | | 3.3 | 5.5 | 8.8 |
| Share of potential dependants in total population (%), 2019 | | | 3.2 | 3.8 | 4.6 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 10.5 | 12.0 | 13.0 |
| Share of population 65+ in need of LTC** (%), 2019* | | 25.9 | 22.6 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 3.9 | 4.7 | 5.5 |
| Share of population 65+ receiving care at home (%), 2019 | | | 7.0 | 8.1 | 8.3 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.4 | 0.3 | 0.3 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 103.8 | 106.6 | 106.8 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 3.6 | 2.9 | 2.5 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 46.8 | 56.3 | | |
| | Women | 49.7 | 62.6 | | |
| | Men | 39.3 | 43.7 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 23.6 | 10.4 | | |
| | Women | 29.8 | 13.7 | | |
| | Men | 15.5 | 6.6 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 17.4 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 4.6 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 1,026.3 | 1,089.1 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 4.4 | 3.7 | | |
| | % Women | | 85.1 | | |
| Share of population providing informal care (%), 2016 | Total | | 9.2 | | |
| | Women | | 11.7 | | |
| | Men | | 6.8 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 35.8 | | |
| | Women | | 34.7 | | |
| | Men | | 37.6 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.1 | 1.1 | 1.5 | 2.0 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.1 | 1.1 | 1.7 | 2.8 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 61.7 | 72.8 | 76.9 | 82.2 |
| Public spending on home care as % of total LTC public spending, 2019 | 20.6 | 7.2 | 7.1 | 6.6 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 17.8 | 20.0 | 16.1 | 11.2 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | - | 1.1 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | - | 0.6 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# THE NETHERLANDS

***Highlights***

- Long-term care (LTC) for older people falls within the scope of the general LTC system. This system is complex and fragmented, though providing extensive rights for those in need of LTC. Governed by different frameworks, it is funded from different sources and organised at different administrative levels. Health and social care and support, and formal and informal care, are mixed. The LTC system includes housing arrangements as well.
- The major 2015 system reform, aimed at quality, community involvement and financial sustainability, is focused on longer independent living (for older people) and access for the most vulnerable. Subsequent initiatives mainly concern improvement of the quality and affordability of institutional and home care, and the corresponding labour market agenda.
- Since the system reforms in 2015, there have been several unexpected and unwanted effects on LTC practice. People abandoned care provisions due to high levels of self-contribution. The transition from home care to residential care proved to be difficult due to regulations. After 2015, the national government and local authorities took measures to change these effects, leading to easier and more affordable access to LTC.
- The main opportunities countering the challenges are (technological, organisational and social) innovation, better integration of both health and social care and formal and informal care, management of needs, expectations and possibilities, and the abolishment of factors complicating the provision of LTC. Increased flexibility, a match between policy and societal views and field work contributions are identified as favourable conditions.

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The Dutch population is expected to increase in the coming decades, from 17.3 million inhabitants in 2019 to 18.0 million inhabitants in 2030 and 18.1 million inhabitants in 2050.[681] The growing population is ageing significantly. In 2050, over a quarter of the population is projected to be older than 65, namely 26.4 % (4.8 million people), as opposed to 19.2 % (3.3

[681] All data used in the text come from Section 5, 'Background statistics' unless explicitly stated otherwise.

million people) in 2019 and 23.5 % in 2030 (4.2 million people)[682]. Within the older age category, women form the largest group.[683] A growing share of the population will be over 75 (8.1 % in 2019, up to 11.5 % in 2030 and 16.0 % in 2050) and those over 80 years old according to Statistics Netherlands (*Centraal Bureau voor de Statistiek, CBS*) (0.8 % in 2020, up to 1.2 % in 2030 to 2 % in 2050).[684] By contrast, over the course of the next decades, there will be fewer younger people of working age. In fact, the Old-age dependency ratio will increase significantly, from 29.5 in 2019, to 38.3 in 2030 and to 44.8 in 2050.

Notably, there are significant regional differences in the degree of ageing, according to Statistics Netherlands and Netherlands Environmental Assessment Agency (*Planbureau voor de Leefomgeving, PBL)*. [685] In non-urban regions on the outskirts of the Netherlands (especially in the South-west (*Zeeland*), but also in the North (*Oost-Groningen*), the East (*de 'Achterhoek'*) and the South-east (*Limburg*)), the share of older people has risen faster than in the urban centre; the conurbation of Western Holland (*de 'Randstad'*). The 'oldest' areas are usually also known as shrinking regions (*krimpregio's*): regions with the strongest population decline, due to young people leaving these areas. The regional projection indicates regional differences in the increase in the coming 15 years (with over 30 % of the population being 65 and older in some shrinking regions), after which a decrease will set in.

If the trends of the past decades continue, the increasing numbers of older people will not only live longer, but will also spend a longer part of their lives in good health. Life expectancy at the age of 65 is 20.3 years in 2019, with women reaching an older age (21.4 years) than men (19.0 years). According to recent projections of Statistics Netherlands, life expectancy at the age of 65 is increasing from 20.2 years in 2020 to 21.3 years in 2030 and 22.5 years in 2040.[686] Healthy life years at 65 were 9.7 years in 2018, with men (9.9 years) spending a slightly larger share of their last years in good health than women (9.5 years). Healthy life years at the age of 60 are projected to increase, according to Statistics Netherlands.[687]

Notwithstanding apparent differences in care needs between older people (see section 2.1), the shift in the population's age composition implies a significant increase in demand for LTC services as the average need of LTC rises with age. The total number of potential care dependants is expected to rise. The number of potential dependants rises from 1,129,600 in 2019 (6.5 % of the total population), to 1,301,200 in 2030 (7.2 % of the total population), and 1,471,400 in 2050 (8.1 % of the total population).

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[682] According to recent projections of Statistics Netherlands (*CBS*), a peak is reached around 2040. The agency foresees 23 % older people as a share of the total population in 2030 (4.2 million people), 25.5 % in 2040 (4.9 million people), and 25.2 % in 2050 (4.9 million people), see CBS, 'Kernprognose 2019-2060: 19 miljoen inwoners in 2039' (17 December 2019), *Statistische Trends*, Centraal Bureau voor de Statistiek, Den Haag, 2019a; CBS, *Prognose bevolking: kerncijfers, 2019-2060*, 2019b. Both articles www.cbs.nl

[683] The same is true in the central Dutch projections, see CBS 2019a and CBS 2019b.

[684] See CBS 2019a and CBS 2019b. The phenomenon that not only the group of people over 65, but also the group of people over 75 as a share of the Dutch population is growing is referred to as 'double ageing'.

[685] CBS/PBL, 'PBL/CBS Regionale bevolkings- en huishoudensprognose 2019-2050', *Statistische trends*, Centraal Bureau voor de Statistiek, Den Haag, 2019.

[686] CBS, *Geslachtsneutrale levensverwachting op 65e verjaardag*, Statline, 2019.; CBS, *Prognose levensverwachting 65-jarigen*, 1 November 2019, News Item. www.cbs.nl

[687] CBS, *Projecties gezonde levensverwachting 2018-2040*, 2018. www.cbs.nl

## 1.2 Governance and financial arrangements

Effective from 2015, arrangement of LTC has undergone a major reform. Objectives of this change were a) care and support are provided in a person's own home for as long as possible; b) care and support at home are organised on a local (municipal) level, thus providing the essential social context; c) if care at home is no longer sufficient, a person is entitled to residential care.[688] As a consequence, LTC is covered by four laws in total, addressing different target groups. (Long-term) care for children and young people aged under 18 years is covered by the Youth Act (*Jeugdwet*, Jw).

LTC for adults -including older people- falls within the scope of three laws: the Social Support Act 2015 (*Wet Maatschappelijke Ondersteuning 2015, WMO*), the Health Insurance Act (*Zorgverzekeringswet, ZVW*) and the Long-Term Care Act (*Wet Langdurige Zorg, WLZ*). This report will concentrate on the WMO, ZVW and WLZ. The WMO covers people who need specific assistance in order to participate and cope in society (mainly focused on people in their own homes); the ZVW covers insured people who are in need of (specialised) medical care, medicines or devices; and the WLZ covers people who need lifelong care and supervision, 24 hours a day. The nature of the care need is essential in determining the applicable framework.

The 2015 LTC reform, and therefore the current LTC scheme, aims to guarantee three crucial aspects in the longer term, namely: quality of care and support, community involvement in (informal) care, and sustainable financing. In essence, independent living arrangements are pursued to enable seniors to remain living in their homes longer, as well as continued access to (good and affordable) care for the most vulnerable. While highly relying on responsibilities and possibilities of citizens and their social environments, the balance between formal and informal care is shifting towards a larger share of informal care, even though it has already been considerable for decades. In the Netherlands, 9.9 % of the population aged over 65 receives informal care, with regional variations (the highest percentage (11.3 %) in the regions Drenthe and Flevoland; the lowest percentage (8.2 %) in Friesland and Gooi and Vechtstreek).[689] Although the government encourages informal care in various ways, Dutch citizens are not obliged by law to take care of a family member.

At the same time, the (central) Dutch government is withdrawing from LTC, although it is still regulating and facilitating it. In fact, the Netherlands has moved from an integrated national scheme towards a more decentralised scheme involving national, regional and local governance levels, with responsibilities divided between public and private bodies, and between health and social care sectors. As of 2020, 355 municipalities are primarily responsible for care under the WMO, 39 health insurers divided over 11 groups of companies are responsible for care provision under the ZVW and regional care offices (*zorgkantoren*) and WLZ-providers in 31 care regions carry out the WLZ. Whereas municipalities are free to choose their own compensation model (e.g. performance-based, hour-based or combinations),

[688] Even though in some cases a care level comparable to residential care and provided by an residential care provider can be provided at home.
[689] CBS, RIVM and GGD'en, *De Gezondheidsmonitor Volwassenen en Ouderen*, 2016. www.volksgezondheidenzorg.nl

funding under the ZVW is usually performance-based, and funding under the WLZ is based on 'care profiles' that identify the severity of care needs.

The Dutch LTC system combines public financing with private contributions. In 2019 the total public financing of the WLZ was EUR 22,598,027,242, own contributions amounted to EUR 1,804,699,000. Public spending on WMO in 2019 was EUR 5,319,499,000, own contributions were EUR 206,718,000.[690]

More specifically, the WMO is financed partly by a state budget which is allocated to and used by municipalities through a fund. Secondly, the WMO is financed by a contribution from the care recipients. Since 2019, this contribution is a fixed amount (a maximum of EUR 19 a month[691] in 2020) which is no longer dependent on income, private means or the nature of the care or provision the person receives. There still is an income based own contribution for sheltered housing. The ZVW is primarily financed through 'nominal' premiums, paid to the health insurers by all insured persons aged 18 and over, and income-dependent contributions which are paid by employers. For children and young people up to age 18, the government pays the costs of the insurance from a tax-based government grant. The WLZ is financed through the LTC Fund (*Fonds Langdurige Zorg*) by income-dependent premiums (automatically deducted from wages or benefits by the tax authority), government contributions, including a tax-based government grant, and personal contributions (co-payments) that are income dependent. The amount of care is not relevant for the co-payments. Public expenditure on LTC in the Netherlands, 3.7 % of GDP in 2019, is relatively high, compared to the EU-27 average of 1.7 %.[692]

## 1.3 Social protection provisions

WMO-support is a form of social assistance, not a social security benefit. The WMO is a framework legislation: municipalities have, within this framework, discretionary power to design local policy. The WMO lays out the general goals (the ability to cope for oneself and participation in society) and stipulates general rights (such as the right to receive the support as a personal budget instead of receiving it in kind). The municipality must adopt bye-laws in which they can lay down access criteria and assessment mechanisms. On top of residence-based conditions (Dutch citizenship, lawful residence and, usually, residency in the municipality), the eligibility for social support provisions is primarily based on the individual needs (such as disabilities or psychological/psychosocial problems of a chronic nature). The ability of the client themselves and their family and or network is also taken into account. If a client could and should apply for care provisions under the WLZ, the WMO is not applicable. Access is usually provided through 'WMO consultants' (WMO-consulenten) and/or social neighbourhood teams (sociale wijkteams, SWTs), that conduct intake procedures, usually by visitation. There is no objective standard determining what sort of need requires what form of care and support; the professionals judge each case on its own merits and also appeal to

[690] CBS and Zorgcijfersdatabank.nl
[691] Local authorities have the possibility to decrease this contribution.
[692] 2018 Ageing Report.

individual and social network responsibilities. Follow-ups can take place in the course of re-indication (WMO consultants or SWTs) or evaluation (municipality or providers).

Every person living or working in the Netherlands is required to purchase a basic health insurance policy (*zorgpolis*) with a health insurance company. With this policy, they are entitled to care in the basic health care insurance package of the ZVW. The care policy of the insured person establishes their rights and obligations; it contains the conditions for insurance coverage. There are four main types of care policies that people can choose from, balancing monthly premium payments, free choice of care providers and insurance coverage. To different forms of care, specific conditions, limitations and/or exclusions apply. For some forms of care, including home nursing care, a referral is necessary. The needs assessment is performed by a care professional, who makes the (medical) diagnosis and reviews the situation and necessary care. A referral of a General Practitioner (GP) is needed for patients who wish to see a medical specialist.

Furthermore, anyone who is permanently in need of 24-hour care nearby or support in the locality can claim WLZ-care; age is not relevant. In order to receive WLZ-care, the Care Assessment Agency (*Centrum Indicatiestelling Zorg*, CIZ) has to issue an indication decision and assesses whether someone is eligible for care under the WLZ.

To lighten the large costs of care, there are several possible cash and in-kind benefits for the person receiving care. Via municipalities, who are free in organising benefits and setting conditions, three possible arrangements apply, namely: collective health insurances, arrangements that pay for extra costs (*meerkostenregelingen*), and special assistance (*bijzondere bijstand*). Via the tax authorities (*Belastingsdienst*), it is possible to apply for care allowance (*zorgtoeslag*) or tax deduction of healthcare costs. Lastly, it is possible to spread payments of own contributions, by applying for payment arrangements (*betalingsregelingen*) via the health insurer. For the informal carer, there are also several possible benefits, most important of which are municipal benefits (e.g. tokens of appreciation or parking permits), relief mechanisms (e.g. respite care), additional health insurance, tax deduction, and extra allowances.

Other (procedural) safeguards exist, including a duty of care for health insurers, enhanced transparency and client-choice, independent client support, complaint procedures, and systematic reviews of needs (i.e. client satisfaction surveys).

## 1.4 Supply of services

Although the different LTC system laws have their own focus, they may cover overlapping services. Under the WMO, general provisions (*algemene voorzieningen*) and personal provisions (*maatwerkvoorzieningen*) are available, such as household services, devices, home adjustments, transport, social support and daytime activities, but also sheltered housing and day-care. The ZVW provides (specialised) medical care such as general practitioner care or specialised medical care and also medicines and devices, but for the older population in need of LTC district nursing care is most important. Lastly, the WLZ offers an integral package of intensive 24-hour care and treatment, including nursing care, residence in an institution, medical care, social support, daytime activities, devices, transport, and household services.

All in all, a range of services are available, varying from light (social) support to more comprehensive (medical) healthcare. Also, for all three legal schemes, both a Personal Care Budget (*Persoonsgebonden Budget*) and in-kind provision is possible.

Care for older people is for a large part comprised of traditional nursing, caring and care at home (*Verpleging, Verzorging en Thuiszorg*). Institutional forms of nursing are significant (16 % of all people aged 80 and over receive care in an institution), but home care (district nursing and informal care) is gaining ground. Also, (institutional) medical forms of care (care in hospitals, mental health care, GP care) are well-represented. All in all, the balance is slowly shifting towards home and informal care (30 % of all people aged 80 and over receive care at home).

Municipalities can provide different levels and types of services within the legal framework. Under the WMO, municipalities can provide (public, not-for-profit) support themselves or may contract care providers, while care under the ZVW is provided by insurers and providers that come under regulated competition, and regional care offices contract WLZ-providers. Service providers are usually private (for-profit) entities that work under public preconditions. Besides public and private service providers, NGO's and individual volunteers are also important in providing social care.

The size of the LTC workforce is 8 workers per 100 individuals aged over 65. The vast majority of these formal LTC workers (94.3 %) are female. Also, a large (and increasing) share of the population (36.7 %) provides informal care, while the reliance on informal care is increasing. Informal care is relatively equally divided between women (38.3 %) and men (35.1 %), but women are still overrepresented.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

The Dutch LTC system is facing several actual and future challenges relating to ageing, the first of which is the challenge of ensuring (affordable) access to formal LTC services.[693]

When it comes to the *affordability* of LTC services, some relevant data is available. First of all, household out-of-pocket payment as percentage of GDP lies at 0.1 % or 0.2 %. An LTC-user may be faced with three different types of out-of-pocket payments. First, in the health care insurance (ZVW) every insured person has to make a fixed, yearly co-payment (EUR 385 in 2020). Health insurers may exclude certain types of care from a co-payment. Secondly, care and support from the Social Support Act (WMO) requires a fixed co-payment per month (maximum of EUR 19 in 2020). Municipalities may decrease this co-payment, according to a person's income and his personal situation. Thirdly, the co-payment for care provided in the Long-Term Care Act (WLZ) is based on the income and personal situation of

[693] See also Cravo Oliveira Hashiguchi, T. and A. Llena-Nozal, 'The effectiveness of social protection for long-term care in old age: Is social protection reducing the risk of poverty associated with care needs?', *OECD Health Working Papers*, No 117, OECD Publishing, Paris, 2020. https://doi.org/10.1787/2592f06e-en

the person receiving LTC. A person with a partner living at home pays a lower amount (between EUR 168.00 and EUR 881.60 per month) than single person (not exceeding EUR 2419.40 per month). A person making co-payments based on the WLZ, is exempt from co-payment for services under the Social Support Act (WMO).[694]At the same time, formal LTC benefits are widely taken up.

Quantitative research of Statistics Netherlands (LTC Monitor) indicate a downward trends of the own contribution, that also applies to people older than 65. Between 2015 and 2019 the average co-payment has decreased for both WLZ care and in-home care via the WMO.[695]

In any case, the Dutch government is paying close attention to downsizing high and accumulating costs for LTC (see section 3), which improves access to services, also for older persons. Indeed, there appears to be a correlation between (high) costs and care usage. The WMO personal contribution has been set at a fixed amount since 2019. A relatively large share of households in need of LTC are not using professional homecare services for financial reasons (30.3 %).[696] Similarly, an unclear but noteworthy number of older people in need of residential care were refraining from taking up the services, due to high out-of-pocket expenses. This situation changed with the introduction of new rules in 2018. Older people waiting to be admitted to residential care receive sufficient care at home without the obligation to pay the out-of-pocket expenses for residential care. Still, a significant share of the population aged over 65 receives LTC: currently, 5.6 % of the older generation receives care in an institution, 19.1 % receives care at home and 1.2 % receives cash benefits.

Regarding the government policy aimed at minimising out-of-pocket spending, it can be noted that the lowering of spending amounts does not seem to apply uniformly to all forms of care. This may create relative cost differences between different types of care service that can have an impact on the choices made between them. At the same time, given the projected increase in public LTC expenditure (see Section 5 – data table) against the background of population ageing and corresponding increases in demand, maintaining the policies minimising out-of-pocket spending may become more challenging in the future.

To continue, differences within the population aged over 65 in need of LTC may hinder (effective and equal) access to care. Importantly, the older age group is a heterogeneous group.[697] On average, women suffer from physical restraints from a younger age than men. Given the fact that women usually reach an older age, they are expected to spend a somewhat larger share of their lives with physical restrictions. Moreover, a proportion of the older population (both men and women) remains extremely vital, while another – growing – share is facing increasing (chronic and comorbid) health issues and vulnerabilities. Health differences are coherent with socio-economic differences: on average, highly-educated 60-year-olds live three years longer, and remain free of physical restraints six years longer than

[694] 'Eigen bijdragen' for WLZ-provisions are based on income and, partly, financial means of the care recipient. ZVW and WMO have relatively small fixed amounts.
[695] https://www.monitorlangdurigezorg.nl/kerncijfers/eigen-bijdrage/opgelegde-eigen-bijdrage
[696] People using or not professional homecare services by household type, income group, degree of urbanisation and reason for not using professional homecare services [ilc_ats15].
[697] Nza, *Monitor Zorg voor ouderen 2018,* 19 April 2018, 2018. www.nza.nl

peers educated to a low level.[698] Indeed, differences in income appear increasingly decisive in receiving care and benefits. Differences between well- and less-informed people may affect access. In particular, people with a mental disabilities, people with a psychiatric illness and older people experience problems in arranging the care they need. The severity and intensity of care also becomes more dominant, as care institutions are nowadays exclusively filled with (and filtered at) those with very severe care needs. Geographical differences between groups may impact (equal) access to care as well, especially when it concerns WMO-support, as municipalities have ample discretionary power to design local policy with in the levels and type of care within the legal framework. However, as stated by law, all citizens of the Netherlands must be able to turn to their municipality for some kind of support which they need to be able to participate in society and carry on living in their own homes. The changes made in 2015, which were accompanied by financial cuts, did inevitably effect the attribution of care and support. Specifically in domestic support (house cleaning), substantial cuts were made so people had to arrange this themselves or received less hours of domestic support then before 2015. In the years after 2015, a great deal of effort was put into increasing the access and affordability of care and support.

To continue, there are also great concerns about the availability of care. The quantitative and qualitative workforce shortages are challenging (section 2.3). Also, the (projected) shortages in available quantities of services and beds in institutions are striking. A noteworthy share of households in need of LTC are not using professional homecare services because the services needed are not available (8.3 %). According to recent projections that are taken into account by the Dutch government, the needed institutional capacity will double from 119,000 beds in 2017 to roughly 242,000 beds in 2040, which may not be realised without government intervention. Over the same period of time, there is a challenge to replace approximately 41,000 beds, due to ageing buildings.[699] At the moment, availability is already hampered by the rising waiting lists for residential care, resulting in distressing situations. The number of people waiting has been high for years, and in 2019 consisted of 18,000 individuals and is still growing (more than 75 % of these people receive adequate care at home and are waiting for a place in a nursing home of their preference). The waiting lists are incomplete because some people may refrain from applying due to costs. Since 2020, action has been taken by the government to expand the number of nursing home places. Another pressing issue is the gap between home and residential care, and the lack of suitable housing types covering this gap.[700] This may be relieved by actions by local governments and housing corporations since 2019. These actions consist of first, making an inventory of local needs and gaps in housing and care provision, followed by actions to meet those needs and fill the gaps. Lastly, future access to informal care – although not a formal service – is also at risk: care needs cannot always be intercepted by (more) informal care (see Section 2.3), potentially leaving those in need of care with unmet needs.

[698] CBS, 'Steeds langer leven zonder beperkingen', *Prognose*, 19 March 2018, 2018. www.CBS.nl
[699] Hinkema, M., van Heumen, S., and Wissekerke, E. N., *Prognose capaciteitsontwikkeling verpleeghuiszorg*, TNO, 2019.
[700] See de Klerk, M., Verbeek-Oudijk, D., Plaisier, I., and den Draak, M., *Zorgen voor thuiswonende ouderen*, 17 april 2019, Sociaal en Cultureel Planbureau, 2019. www.scp.nl

## 2.2 Quality

In the Netherlands, several developments are increasingly exerting pressure on the (future) deliverance of good quality LTC, in particular for the older population. Importantly, the (future) system is not only facing a *rising* but also a *changing* demand for care for older people, mainly due to a combination of medical factors (e.g. more complex and comorbid care needs, dementia and mental limitations) and societal expectations (i.e. emphasis on psychosocial aspects in care, including autonomy, meaningful activities and quality of life). Accompanying costs will rise. This leads to an increasing need for different forms of care and for highly skilled care professionals.[701] The supply chain (in both general LTC and LTC for older people), however, faces short- and long-term shortages in adequate quality care professionals, next to a projected decline in the number of available informal carers. At the same time, there are rising financial shortages. All in all, it appears increasingly difficult to meet the growing demand for quality of care for the older population under the constrained resources. In particular, the lacking quality of residential care has long been criticised.

For the above reasons, a major goal of the 2015 reform and system was enhanced quality assurance. However, some key system characteristics may in turn impact on the quality of (older person) care. First of all, the strong emphasis on longer living at home by older people and the accompanying reliance on home care and unskilled informal carers may make it more challenging to ensure quality of care. Typically, home care quality is less regulated than residential care, while ensuring the quality of informal care is challenging by its very nature. Secondly, the fragmentation of administrative responsibilities and highly differentiated care services poses a risk to (equal) quality in different care settings, partly given differences in funding and public investments or cuts. In fact, district nursing is under increasing financial pressure (see section 2.4). Also, research has shown a lack of coordination and cooperation surrounding older people who remain living at home, for example, between formal and informal carers, and between GPs and district nurses.[702]

Key policies and practices to ensure quality in LTC (for older people) are regulation, accreditation and certification, financial stimulation, transparency, accountability and monitoring.[703] In the period 2015-2021 the Government has invested EUR 2.1 billion to improve nursing home quality, mainly by employing more personnel. In the area of LTC for older people, several norms and quality standards are in place (e.g. regarding dementia, care for people with disabilities, and those with psychological illnesses). The two most important quality standards are the 2017 Quality Framework for Nursing Home Care (*Kwaliteitskader Verpleeghuiszorg*) and the 2018 Quality Framework for District Nursing (*Kwaliteitskader wijkverpleging*). Firstly, these quality frameworks contain minimum quality conditions and obligations for the parties responsible. Whereas the first framework (for residential care) is focused on 'learning and improving together' in the sector, on the client and safety, and on the composition of personnel, the second (for district nursing) -aiming at both quality

[701] See Nza, 2018.
[702] See for example the research of the Health and Youth Care Inspectorate (IGJ), 2019. https://www.igj.nl/onderwerpen/zorgnetwerken/toezicht-op-zorgnetwerken-rond-kwetsbare-ouderen and SCP.
[703] These mechanisms are discussed in more detail in the 2019 ESPN Dutch profile on LTC quality assurance.

improvement and uniformity in care- stresses prevention, the client and 'learning and improving'.

Secondly, the applicable quality frameworks serve as a basis for quality assessment, enforcement and improvement, for accreditation and certification and for contracting and accountability. This is true for all care settings. The various monitoring and accountability schemes (and bodies) use varying indicators for quality such as use, accessibility, expenditure and client satisfaction. Whereas negative financial pressures largely come down to loss of contracts or fines upon non-compliance of quality standards, positive impulses are abundant, including (temporary or continual) subsidies for quality improvement programmes, initiatives and organisations. Accreditation and certification schemes mainly consist of mandatory public registrations for care professionals (e.g. the BIG-registration based on the Individual Healthcare Professions Act (*Beroepen in de Individuele Gezondheidszorg*, BIG), mandatory admission requirements for care institutions on the basis of the Care Institutions Accreditation Act (*Wet toelating zorginstellingen*, WTZI), and voluntary quality labels for institutions, that are strongly advised and increasingly looked at. Similarly, transparency of quality (and consumer choice) is increasingly stimulated.

Quality of informal care is (indirectly) stimulated and facilitated by support mechanisms (see sections 2.1 and 2.3). Also, care institutions and professionals are instructed to enhance involvement of informal carers in care and related processes. In particular, active and constructive collaboration and knowledge exchange have become primary concerns, especially in home-based care. In addition, the situation of the informal carer is monitored.

Challenges remain. As the different quality frameworks hinder information-exchange between professionals and lead to more complexity and bureaucracy, recently a there has been a cry for one overarching quality framework covering care for older people.[704] Also, the degree to which the quality conditions can actually be implemented in light of the financial and workforce constraints is questioned.

## 2.3 Employment (workforce and informal carers)

Another pressing challenge in providing LTC to older people is to *recruit* and *maintain* a formal workforce and informal carers of the necessary size and composition in the short-term as well as in the long-term. At the moment, there are striking workforce shortages in the various relevant care sectors, both in number (quantity) and in demanded requirements (quality). There are 8 LTC workers per 100 individuals aged over 65, a high percentage of these are female (94.3 %). Given the rising and changing demand for good quality care (see section 2.1), projections foresee rising shortages. Indeed, according to the Dutch Central Planning Bureau (*Centraal Planbureau. CPB*) the yearly employment growth in health care is 2.1 % in the short-term (between 2022 and 2025).[705] This relates to labour productivity of 0.8 %, which is somewhat lower than that of the market. Not only is the influx of sufficiently qualified care professionals falling short, but also the outflow is relatively high.

[704] See http://www.actiz.nl/nieuws/nieuwe -verwachtingen-ouderenzorg-nodig-de-hoogste-tijd-voor-een-landelijk-debat
[705]Zeilstra, A., den Ouden, A. and Vermeulen, W., 'Middellangetermijnverkenning zorg 2022-2025', *Notitie*, November 2019, CPB, 2019. www.cpb.nl

Recent research focusing on this outflow identifies ten main reasons for leaving the care sector.[706] In order of importance, these are (failing) career opportunities, challenging tasks, organisation of work and management, working atmosphere and cooperation, work content, travel distance, salary and working conditions, private matters, contracted hours/type of contract, and working hours. For care in nursing homes and home care, the top three of reasons are (failing) organisation of work and management, working atmosphere, cooperation and challenging tasks. Other identified reasons for difficulties in relation to both *recruitment* and *retention* are the (experienced) physical and mental burden on care professionals, due to a high workload and administrative pressure (resulting in absenteeism), the low attraction and image of working with older people in the care sector.[707] Many policy initiatives (e.g. campaigns to improve the image and better education), that are widely supported, are in place to attract and maintain personnel, taken the above mentioned factors into account (see section 3).

Informal care is an important part of LTC. Of the almost 5 million informal carers, 830,000 provide intensive informal care (more than 8 hours a week) for a prolonged period of time (more than three months)[708]. This makes them an essential addition to formal care. As can be seen in section 1.4, informal care is most often carried out by women according to the Netherlands Institute for Social Research (*Sociaal en Cultureel Planbureau, SCP*). Still, men are well represented, especially in supporting their partners. Although other age groups, including adolescents and older people, also provide informal care, informal care is often provided by people between the ages of 55 and 64, mostly due to the ageing of their parents. (SCP, 2019) Whereas 17 % of informal carers provide support for more than eight hours a week, 3.3 % of the informal carers provides support for more than 20 hours a week (SCP, 2019).

According to research, the willingness to provide informal support is relatively high, also within those that are not providing care at the moment (about a quarter of the 'non-helpers' are willing), especially when it concerns family members. Nevertheless, the actual future potential of the informal workforce is difficult to estimate. Identified barriers for potential caregivers include, for example, being unable to recognise care needs or being unable to act out of fear (*handelingsverlegenheid*), for example to offend the person in need of care. Moreover, there are important boundaries for (potential) caregivers, including lack of time, lack of competences, unwilling care recipients and dealing with the burden of caring. In fact, about one in ten informal carers experience a high level of burden, which may, in turn, negatively affect care recipients. High risks of overburdening occur in relation to dementia, psychological issues and terminal situations. Migrant and older informal carers are mentioned by the government as groups that deserve special attention. However, knowledge on these groups is lacking (SCP, 2019).

[706] Regioplus and Presearch (2019). *FACTSHEET 2019 Eerste resultaten structureel landelijk uitstroomonderzoek*. www.regoplus.nl. This research is mentioned in political debates.
[707] Arbeidsmarktagenda (2017). *Arbeidsmarktagenda 2023. Aan het werk voor ouderen!* 12 July 2017, several cooperating parties, authors unknown.
[708] SCP, 2020-17, *Blijvende bron van zorg*.

Many support measures are in place for informal carers, including financial benefits (e.g. respite care and tokens of appreciation) (see section 1.3), enhanced cooperation with care professionals (see section 2.2), (practical) information and advice, social and emotional assistance, and training (e.g. with online courses). In essence, informal caregivers can turn to municipalities, local or national interest groups, and care providers for support. However, research shows that a quarter of the informal carers that could apply for support, are not familiar with the options and processes. Also, skills are not validated. The government works together with organised interest groups (for older people, for migrants, for young carers) and employers' associations to find ways to increase and improve the support for each specific group of informal carers. This should also be helpful to anticipate the growing demand for informal care.

It is expected that the pressure on informal care will rise over the coming decades along with the corresponding care burden, due to older people with complex health issues and more chronic illnesses living longer at home , decreasing numbers of informal caregivers per person cared for, shortages in the formal workforce and rising health costs. Given the abovementioned boundaries and burden, it must be stressed that the decrease in formal care cannot (always) be compensated for by (more) informal care (SCP, 2019).

## 2.4 Financial sustainability

In the Netherlands, the financial sustainability of LTC (for older people) has been debated for a long time. In the decades before 2015, public expenses for LTC had grown so heavily, that far-reaching measures were deemed necessary, especially given the projection of rising costs, partly attributed to ageing and the corresponding rising demand for care, and less people of working age to pay for them.[709]

Public expenditure on LTC, established at 3.7 % of GDP in 2019, is high, also in comparison to other countries. It is projected by the the 2021 Ageing Report[710] to increase substantially over the coming decades, both in the reference scenario (4.5 % in 2030 and 6 % in 2050) and the risk scenario (4.7 % in 2030 and 6.7 % in 2050). By far the largest proportion of the budget for (long-term) care is used by the ZVW and the WLZ. Indeed, the majority of the current and projected public expenditure is spent on residential care (51.0 % in 2019, 53.9 % in 2030 and 59.5 % in 2050).It has proven difficult to put these figures in perspective by highlighting the budgetary cost associated with informal care, as this information is not readily available. It is, however, expected that the rise of public expenditure is mitigated by the increased emphasis on personal responsibilities and community involvement, including informal care, and by budgetary cuts.

The budgetary cuts of the 2015 reform seems to have paid off in the first years. The higher barrier for admittance to nursing homes resulted in diminished expenses. Also, municipalities were able to execute the WMO more cost efficiently, and health insurers ensured a strong

[709] See for example *Notitie Hervorming van de langdurige ondersteuning en zorg*, 2013. https://zoek.officielebekendmakingen.nl/blg-224333.pdf

[710] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

under-utilisation of resources for home care (about EUR 300 million). Yet, under increasing societal pressure, many budget cuts on care for older people were recently alleviated, especially in relation to nursing institutions (see Section 3). At the same time, other sectors with limited growth opportunities, including district nursing, are under more financial pressure. All in all, it is not easy to lower public spending on LTC for older people.[711]

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Similar to the practices discussed in relation to care for older people, care for children and young people under the Youth Act is surrounded by challenges. Most debated are the long waiting lists for residential care, especially for young people in need of psychological or psychiatric care. Also, the 18-/18+ transition is a recurring issue. Recently, there are signals that children with developmental issues are not always receiving the care they need. In these cases, the Youth Act rarely suffices.[712]

# 3 REFORM OBJECTIVES AND TRENDS

As described in Section 1.2, the Dutch system of LTC was reformed drastically in 2015, with a view to ensuring (future) quality, more involvement of society and viable financing, stressing longer independent living against access for the most vulnerable. Since the government has focussed on 'improvements' along these lines, more than on far-reaching 'reforms'.[713] Still, LTC remains a policy priority, which means that relevant initiatives by care providers, insurers and NGO's are embraced and measures are being taken. Importantly, there is much political and societal attention on providing good care for *older people*. With the current policy the government wants to optimise the healthcare system though ensuring the right care in the right place, preventing unnecessary/ expensive treatment, relocating healthcare from institutions to home and substituting obsolete services for better alternatives (e.g. E-health).

Recent measures *specifically concentrated on the older population* mainly concern the quality and affordability of institutional and home care, and the (informal) workforce.

To be more specific, a stimulus is given to quality, in the first place by enhanced regulation and monitoring of the quality of (informal) care practices at home (see Section 2.2). On the basis of the 2018 'Pact for Older People Care' (*Pact voor de Ouderenzorg*), the 2018 programme 'Ageing in Place' (*Langer Thuis*) and the 2017 Manifesto 'Dignified ageing' (*Waardig ouder worden*),[714] attention goes to, for example, the presence or absence of social support (e.g. to fight loneliness) care and needs correspondence, integrated support and care,

[711] See Zorgvisie (2018). *Betaalbaarheid ouderenzorg is niet opgelost*. https://www.zorgvisie.nl/betaalbaarheid-ouderenzorg-is-niet-opgelost/
[712] Young people with mental disabilities have access to WLZ care.
[713] For more information and details on the measures discussed, see *Regeerakkoord 2017 'Vertrouwen in de toekomst'*, https://www.rijksoverheid.nl/documenten/publicaties/2017/10/10/regeerakkoord-2017-vertrouwen-in-de-toekomst.
[714] This Manifesto was launched in 2017 by the public broadcast corporation for people older than 50 (*omroep Max*), senior citizens' organisation KBO-PCOB, and the Christian-democratic political party in the Netherlands (*Christenunie*), and has been embraced by the government in the beginning of 2019.

informal caregivers and volunteers, housing, and the quality of assessment-procedures. To this end, government investments (after an injection of EUR 180 million, 30 million each year) and a WMO-evaluation are in place. In the second place, several ambitious plans for improving quality of residential care apply, and large government investments are made (structurally EUR 2.1 billion) to facilitate compliance to quality norms in practice. Next to the search for highly qualitative care professionals, a different organisation of working and organising (e.g. small scaled, demand- and thus client-oriented and innovative) is stressed. Improved quality must be demonstrated; providers will be judged on this, but at the time of writing it is not yet clear in what way.

To continue, three of the most important measures to enable affordability and counter the accumulation of contributions (see Section 2.1), are the fixation of the required own risk at EUR 385 a year, the yearly fixation of the contribution (*abonnementstarief*) for WMO-provisions (as well as for the PGB), in 2019 at EUR 17.50 and in 2020 at EUR 19.00 per month, and the maintenance of the anti-cumulation scheme: when a household already pays the contribution for WLZ-care, than this is not required for personal WMO provisions.

To counteract the workforce challenge, the labour market agenda (the 'labour market agenda 2023: Working for older people' (*Aan het werk voor ouderen*), launched in 2017, along with the general action programme 'Working in health care' (*Werken in de Zorg*), launched in 2018), aimed at the future availability of sufficient and well-educated care professionals, is ambitious in scope. Eleven action points are specified in relation to care for older people, that largely come down to improving the attractiveness of the sector (e.g. by campaigns to improve its image) and working conditions (e.g. quality of work, job certainty), better education (e.g. qualifications and (re)training), and working in a different way (e.g. (inter) sector cooperation, innovation, matching demand and supply). Regions and municipalities are important in the execution. In relation to informal care, possibilities for care leave and flexible work are expanded.

Within the broader health system, reform measures that are also relevant for the older population are taken in regards to financial, administrative and social protection arrangements. These were announced in the Coalition Agreement (*Regeerakkoord*) of 2017. The action programme '(De)Regulating care' (*Ont)Regel de zorg*)), launched in 2018, aims at decreasing administrative burdens, by 'scraping' rules and diminishing bureaucracy. Also, measures are currently being taken to ensure healthy competition, a reasonable price-quality balance and money usage for care and not profit, including conversations between government and private insurers and providers, stricter public preconditions (e.g. a prohibition of profit distribution and specific requirements for public contracting). Lastly, measures relating to innovation (e.g. e-health) and the quality of life (e.g. local approaches combating loneliness) are emphasised by the government. In the Netherlands, COVID-19 and the associated measures also impact on LTC (for older people) and the position of involved clients, professionals and informal carers.[715] On the one hand, access to (home and informal) care and daytime activities are in many cases reduced for the older population, both by formal

[715] For an example, see the website of the central government. https://www.informatielangdurigezorg.nl/soorten-zorg/corona

measures (e.g. social distancing) and by client choices (e.g. refusing care out of fear). Also, there are possible negative financial consequences for care providers and care professionals, as well as possible mental health consequences for informal carers. On the other hand there is extra attention for the most vulnerable in society, including older people in need of LTC, with -indirect- positive effects. For example, COVID-19 prevention and testing in residential care facilities has been made a high priority, for clients, care workers and informal carers. The regional approach for achieving extra bed capacity to protect the most vulnerable from the virus and to guarantee safe care (filling a gap between home care and intensive care) can serve as another example. Increasingly, initiatives to tackle loneliness are embraced by the government and by society as a whole, and creative (daytime) activities and initiatives are in turn invented for older people. In order to prevent care providers from financial collapse, the Dutch Ministry of Health, Welfare and Sport (*Volksgezondheid, Welzijn en Sport*, VWS), the National Healthcare Institute (*Zorginstituut*), and the Dutch Healthcare Authority (*Nederlandse Zorgautoriteit*, Nza) combined forces to offer financial support. Support for involved informal carers is also promoted. Furthermore, a harnessing of digital innovation (e.g. ensuring digital communication) is apparent, both in home and residential care for older people. Another possible trend may be a boost to the image of working in healthcare and LTC. However, it is too soon to judge whether the abovementioned developments will have lasting effects.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The main (future) challenges in the provision of LTC for older people are equal and affordable access to care and the availability of suitable services, financial sustainability of the system, quality of services and professionals, and formal and informal employment shortages that coincide with an increased reliance and burden on formal, and especially, informal care. These challenges relate to the growing but also increasingly complex health issues of the ageing population.

Still, there are certainly opportunities in addressing the LTC challenges, most important of which are:

- technological and social innovation (e.g. in the form of e-health, smart devices, and improved communication methods for clients), in order to keep service delivery of high quality and financially viable, affordable and accessible, potentially also lowering the needed involvement of (informal) carers;
- organisational innovation (e.g. introducing new, small-scaled or comprehensive service types filling the gap between home and residential care and improving formal structures in care organisations), to meet both client and workforce needs;
- more tuning, learning and cooperation between relevant sectors and actors, mainly in health and social care and formal and informal care, to improve efficiency, quality and satisfaction for all those involved;
- better management of needs, expectations and options, ensuring suitable services of the necessary quality and involving only the necessary care, thereby enhancing financial

sustainability and equal access for all in need of care, and improving client satisfaction and wellbeing;

- abolishment of unnecessary complicating factors in the delivery of care and benefits (e.g. fragmentation of rules, procedures and services, and administrative burdens), improving access to clients (and their social environment), and improving working conditions for formal care workers.

Several factors shape favourable conditions:

- those involved (e.g. health insurers and providers) are contributing strongly to the political debate, which is necessary for policy to match issues in a practical way;
- the system appears to be becoming more flexible, given the many initiatives and adjustments, which may be very useful in the future;

  the increased attention to core values such as dignity and quality of life matches present-day societal expectations, which, in turn, might slowly create a support base for the needed (solidary) financial and workforce motivation.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 16.4 | 17.3 | 18.0 | 18.1 |
| Old-age dependency ratio, 2019 | | 21.8 | 29.5 | 38.3 | 44.8 |
| Population 65+ (in millions), 2019 | Total | 2.4 | 3.3 | 4.2 | 4.8 |
| | Women | 1.4 | 1.8 | 2.2 | 2.6 |
| | Men | 1.0 | 1.5 | 2.0 | 2.2 |
| Share of 65+ in population (%), 2019 | | 14.7 | 19.2 | 23.5 | 26.4 |
| Share of 75+ in population (%), 2019 | | 6.8 | 8.1 | 11.5 | 16.0 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.5* | 20.3 | | |
| | Women | 21.0* | 21.4 | 22.5 | 24.5 |
| | Men | 17.7* | 19.0 | 19.9 | 21.8 |
| Healthy life years at the age of 65, 2018 | Total | 9.5* | 9.7 | | |
| | Women | 9.5* | 9.5 | | |
| | Men | 9.4* | 9.9 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 1,129.6 | 1,301.2 | 1,471.4 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 484.9 | 677.0 | 890.5 |
| | Women | | 309.5 | 407.5 | 546.9 |
| | Men | | 175.4 | 269.5 | 343.6 |
| Share of potential dependants in total population (%), 2019 | | | 6.5 | 7.2 | 8.1 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 14.5 | 15.9 | 18.6 |
| Share of population 65+ in need of LTC** (%), 2019* | | 29.6 | 26.9 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 5.6 | 6.3 | 8.8 |
| Share of population 65+ receiving care at home (%), 2019 | | | 19.1 | 21.2 | 26.2 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 1.2 | 1.3 | 1.8 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 171.3 | 173.2 | 188.7 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 8.1 | 8.2 | 9.7 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 24.2 | 24.5 | | |
| | Women | 25.4 | 28.5 | | |
| | Men | 22.2 | 16.4 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 21.3 | 18 | | |
| | Women | 28.0 | 23.6 | | |
| | Men | 13.4 | 11.6 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 30.3 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 8.3 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 1,422.4 | 1,370.7 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 11.1 | 8.0 | | |
| | % Women | | 94.3 | | |
| Share of population providing informal care (%), 2016 | Total | | 36.7 | | |
| | Women | | 38.3 | | |
| | Men | | 35.1 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 3.3 | | |
| | Women | | 3.2 | | |
| | Men | | 3.4 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 4.1 | 3.7 | 4.5 | 6.0 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 4.1 | 3.7 | 4.7 | 6.7 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 86.6 | 51.0 | 53.9 | 59.5 |
| Public spending on home care as % of total LTC public spending, 2019 | 13.4 | 16.4 | 16.7 | 16.5 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 0.0 | 32.6 | 29.4 | 24.0 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 2.7 | 2.5 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 1.2 | 1.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.3 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.1 | 0.1 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# AUSTRIA

***Highlights***

- The Austrian long-term care (LTC) regime provides a mix of LTC cash benefits and a wide variety of LTC services.
- Responsibilities are split between the Federal Republic (LTC cash benefits) and the federal provinces (LTC services).
- Regarding LTC services, a strong differentiation exists between federal provinces concerning coverage rates by different LTC systems, regarding quality standards and instruments for quality assurance, in the area of needs assessments and future planning and also concerning the actual costs to be covered from private resources.
- Additional substantial challenges exist regarding financial sustainability, concerning the problematic effects of informal care (e.g. substantial stress and strain for informal carers, adverse effects on gainful employment) and the affordability of formal home care services.
- The new Austrian national government, which took office in January 2020, announced a comprehensive reform of the Austrian LTC system. However, details are unclear at the time of writing

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The ageing of the population puts the Austrian LTC system under considerable demographic pressure. Besides health prevention, demographic trends are decisive for the potential need and demand for LTC. At the same time, they imply a reduction of the proportion of people of working age, potentially available to provide formal or informal care.

Over the last decade the share of the population aged 65+ steadily increased from 17.1 % in 2008 to 18.8 % in 2019 in Austria.[716] This share increased to a somewhat lesser degree than that of the EU-27 average, where the corresponding numbers are 17.3 % (2008) and 20.3 % (2019). The share of people aged 75+ during the same time period increased from 7.9 % to 9.4 % in Austria, and from 8 % to 9.7 % on average in the EU-27. Also, the old-age dependency ratio indicates a somewhat stronger demographic ageing for the EU-27 average than for Austria. The number of people aged 65+ over the number of people aged 15-64 rose

[716] All data used in the text come from Section 5, 'Background statistics' unless explicitly stated otherwise

from a level of 25.7 % in 2008 to 31.4 % in 2019 on average in the EU-27, and from 25.4 % to 28.2 % in Austria.

Future projections expect strong demographic ageing both for Austria and for the EU-27 as a whole. The share of people aged 65+ is expected to rise from 18.8 % of the population in 2019 in Austria (EU-27: 20.3 %) to 22.8 % in 2030 (EU-27: 24.3 %) and then further to 27.2 % in 2050 (EU-27: 29.3 %). At the same time also the share of the age group 75+ is expected to increase: from 9.4 % in Austria in 2019 (EU-27: 9.7 %) to 10.6 % in 2030 (EU-27: 12.1 %) and to 16.1 % in 2050 (EU-27: 17.1 %). The old-age dependency ratio (number of people aged 65+ over the population aged 15-64) is estimated to increase in Austria from 28.2 in 2019 (EU-27: 31.4) to 36.6 in 2030 (EU-27: 39.1) and to 47.2 in 2050 (EU-27: 52.0). Hereby, some substantial differentiations exist between the different Austrian NUTS-2 regions, which are on par with the federal provinces.[717] Overall, Vienna will continue to have the youngest demographic structure of all federal provinces, while, Carinthia and Burgenland will continue to have the oldest demographic structure of all Austrian federal provinces.

Overall, these demographic trends and projections point towards a very substantial future increase in demand for LTC.[718] According to the AWG reference scenario, the number of people potentially dependent on LTC will rise from around 781,200 in 2019 to around 870,900 in 2030 and around 1.03 million in 2050.[719] According to the same projections their share in the total population will rise from 8.8 % in 2019 to 9.5 % in 2030 and then further to 11.0 % in 2050.

## 1.2 Governance and financial arrangements

According to calculations provided in the 2021 Ageing Report[720] public spending for LTC in Austria amounted to 1.8 % of GDP in 2019 (EU-27: 1.7 %).[721]

As a distinct area of social policy in Austria, long-term care (LTC) is quite new. It was only in 1993 that the two major elements of the Austrian LTC regime and the mutual interaction between them got defined in more detail in an ‘agreement according to article 15a of the Austrian Constitutional Act’ (hereafter: ‘15a agreement’) between the Federal Republic and the federal provinces (*Bundesländer*).[722] According to the 15a agreement, LTC benefits are to be granted both in form of cash benefits and in form of LTC-services and benefits in kind.

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[717] Statistics Austria, population forecast, base scenario and own calculations. For detailed data see https://www.statistik.at/web_de/statistiken/menschen_und_gesellschaft/bevoelkerung/demographische_prognosen/bevoelkerungsprognosen/index.html (accessed 01.06.2020)

[718] See for a discussion focusing on the case of Austria: Grossmann, B. and P. Schuster, *Langzeitpflege in Österreich. Determinanten der staatlichen Kostenentwicklung* [Long-term care in Austria: Determinants of cost development], Study commissioned by Austrian Fiscal Advisory Council, Vienna, 2017.

[719] See Section 5 ‘Background statistics’.

[720] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, European Commission, Brussels, 2021.

[721] See also Section 5 ‘Background statistics’. Note: These data do not only address the ‘health-related’ part of LTC expenditure, as covered category HC.3 of the OECD system of health accounts, but also an estimation for the ‘social-related’ part of LTC expenditure, as covered in category HC.R.1 of the OECD system of health accounts. HC.3 alone recently amounted to 1.5 % of GDP (Source: OECD Database; https://stats.oecd.org/).

[722] BGBl. Nr. 866/1993. See http://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen and Gesetzesnummer=10001280 (accessed 16.04.2020)

LTC cash benefits have been exclusively the responsibility of the Federal Republic since 2012.[723] The federal long-term care cash benefit (*Bundespflegegeld*) is regulated in a specific federal law[724] and granted to people in need of care without means testing (against income or assets) and according to seven different levels, corresponding to a categorisation of seven different levels of individual care requirements. Funding for this scheme comes from the general budget of the Federal Republic, i.e. it is tax financed.

Within the 15a agreement, the federal provinces made a commitment for developing and upgrading the decentralised and nationwide delivery of residential care, day care, and different kinds of formal home care services. This is the second major element of the Austrian LTC-regime. The responsibility for these services and in-kind benefits is at the first instance located at the level of the federal provinces and they are usually subject to private co-payments, depending on the financial income of the person in need of LTC (see below section 2.1 for more details). Related costs covered by the federal provinces and municipalities are financed from their general budgets. The most important sources of revenue for the latter are funds distributed via the so-called financial equalisation scheme (*Finanzausgleich*)[725], which transfers tax revenue from the Federal Republic to the federal provinces and municipalities, and funds from the so-called Long-term Care Fund (*Pflegefonds*)[726], which was first introduced in 2011 and which is also financed from the tax yield.

Apart from the LTC cash benefits and formal LTC services organised by federal provinces and municipalities, a number of other instruments are in place to support people in need of LTC and their relatives.

Within the so-called '24-hour care' (*24-Stunden-Betreuung*), people in need of LTC are looked after by privately hired carers at home (so called live-in carers). This was largely operated by the grey economy until a reform in 2007. The reform legalised this form of privately organised LTC, which is primarily dependent on temporary migrant carers from countries like Slovakia and Romania. Furthermore, the reform also introduced public financial subsidies for such LTC arrangements, which are granted by the Federal Republic under specific circumstances (see below section 2.1).[727] These subsidies are financed via the general federal budget, i.e. they are tax financed.

In addition, two different leave schemes – 'care leave' (*Pflegekarenz*) and 'family hospice leave' (*Familienhospizkarenz*) – allow caring relatives to take some time off from gainful employment or to reduce their working time. For such people, a specific leave-benefit – 'care-leave benefit' (*Pflegekarenzgeld)* – has also been available since 2014. The 'care-leave

[723] For specific groups, also the federal provinces granted this kind of benefit before 2012.
[724] BGBl. Nr. 110/1993 most recently changed by BGBl. I Nr. 80/2019. See http://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen and Gesetzesnummer=10008859 (accessed 16.04.2018).
[725] BGBl. I Nr. 116/2016, most recently changed by BGBl. I Nr. 103/2019. See https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen and Gesetzesnummer=20009764 and FassungVom=2021-12-31 (accessed 16.04.2018).
[726] BGBl. I Nr. 57/2011, most recently changed by BGBl. I Nr. 16/2020. See https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen and Gesetzesnummer=20007381 (accessed 16.04.2018).
[727] For more details see https://www.oesterreich.gv.at/themen/soziales/pflege/1/Seite.360531.html (accessed 16.04.2018).

benefit' is regulated in the same federal law[728] as LTC cash benefits granted to people in need of LTC and also financed from the federal budget, i.e. by taxes in the first instance.

For informal carers some additional consulting and communication services are also offered by a variety of different federal and regional institutions in form of counselling, hotlines, online platforms, etc.

For a long time, data in Austria was unreliable or scarce concerning the distribution of residential care as opposed to home care, as well as regarding the share of informal provision in the total provision of LTC.[729] However, more detailed information has been made available via a research project commissioned by the Federal Ministry for Social Affairs, with results published in June 2018.[730] These results show that by the end of September 2017 around 87 % (about 394,000) of all recipients of LTC cash benefit (*Bundespflegegeld*) lived in private homes, and about 13 % (around 75,500) in institutional facilities (i.e. retirement and nursing homes).[731] For the ones living in private homes different LTC care arrangements exist. In 19 % of all cases, LTC was provided by one informal carer (i.e. usually a close relative) alone, in 35 % of all cases by an informal carer with some help from other informal carers (like friends/relatives etc.).[732] This means in 54 % of cases that LTC for people in private homes is provided through informal care only. In 34 % of all cases there exists a mix of informal and formal support and for 12 % caring relatives are solely supported by formal LTC services of different types (and not by additional people providing informal care).[733]

Regarding the question of regional or geographical uniformity versus differentiation of care arrangements and availability and accessibility of different types of services, it has to be stressed that very substantial differences appear to exist between the different federal provinces (*Bundesländer*). This applies to the actual prevalence of different types of residential care[734] and also concerns issues like private co-payments, quality assurance and assessment of future requirements and related strategies. This very substantial differentiation according to federal provinces and the evident lack of national co-ordination and planning has recently been fiercely criticized in a detailed analysis by the Austrian Court of Audit.[735]

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[728] BGBl. Nr. 110/1993 most recently changed by BGBl. I Nr. 80/2019. See http://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen and Gesetzesnummer=10008859 (accessed 16.04.2018).

[729] See for more details: Fink, M., *ESPN Thematic Report on Challenges in long-term care: Austria 2018*, European Social Policy Network (ESPN), European Commission, Brussels, 2018. https://ec.europa.eu/social/BlobServlet?docId=19837 and langId=en (accessed 17.04.2020), page 8.

[730] See Nagl-Cupal et al., *Angehörigenpflege in Österreich. Einsicht in die Situation pflegender Angehöriger und in die Entwicklung informeller Pflegenetzwerke*, Universität Wien, Vienna, 2018. https://broschuerenservice.sozialministerium.at/Home/Download?publicationId=664 (accessed 18.04.2020)

[731] This information derives from registry data provided by the Austrian Main Association of Social Insurance Providers (*Hauptverband der Österreichischen Sozialversicherungsträger*). Due to data limitations, the number of people in residential care facilities is somewhat underestimated (see Nagl-Cupal et al. 2018, 26f.).

[732] In Austria no legal obligation exists for children to care for their parents.

[733] These data derive from a representative survey undertaken by Nagl-Cupal et al., 2018.

[734] For an overview see https://www.statistik.at/web_de/statistiken/menschen_und_gesellschaft/soziales/sozialleistungen_auf_landesebene/betreuungs_und_pflegedienste/index.html (accessed 17.04.2020)

[735] See Rechnungshof, *Pflege in Österreich. Bericht des Rechnungshofes*, Vienna, 2020. https://www.rechnungshof.gv.at/rh/home/home/004.682_Pflege_Oesterreich.pdf (accessed 19.04.2020)

## 1.3 Social protection provisions

The most important social protection provisions for LTC are, as mentioned above, 'LTC cash benefit' (*Bundespflegegeld*) for people in need of LTC and 'care-leave benefit' (*Pflegekarenzgeld*), granted to caring relatives under specific circumstances.

*Bundespflegegeld* is granted without means testing (against income or assets) and according to seven different levels, corresponding to a categorisation of seven different levels of individual care requirements/the health status of the person in need of care. The benefit currently (in 2020) amounts to EUR 160.10 net a month at level 1 (the lowest level of benefits), but may be as high as EUR 1719.30 net at level 7.[736] The minimum care need, which is a precondition for access to *Bundespflegegeld* of level 1, is 65 hours per month. For the highest level, i.e. level 7, the minimum care need is 180 hours per month. Additional conditions for the latter are a serious disability impeding the use of hands and feet meaning that no precise movements are possible. The needs assessment is based on a doctors' expert opinion.[737] Representatives of other fields (e.g. nursing) are also involved in an extensive assessment of the situation. The expert opinion is usually drawn up after an examination at home. LTC cash benefits are intended to be used to buy formal care services from public or private providers or to reimburse informal care provision. However, there is no controls on what LTC care benefits are actually spent on by the benefit recipients.

'Care-leave benefit' (*Pflegekarenzgeld*) may be granted to caring relatives during 'care leave'[738] (*Pflegekarenz*) and 'family hospice leave' (*Familienhospizkarenz*).[739] Care leave is designated to people looking after close relatives in need of LTC, who obtain a LTC cash benefit of level 3 or above.[740] Family hospice leave is for the purpose of nursing a dying close family member (a LTC cash benefit is not required in this case). The care-leave benefit is in principle calculated according to the rules for unemployment benefit (*Arbeitslosengeld*). This results in a net wage replacement rate of 55 %, plus supplements for dependent children. Take-up of this instrument until recently remained rather low[741], most likely because of these two schemes, the potentially more important 'care leave' did come with a legal entitlement vis-à-vis the employer – the employee and the employer had to agree on it up until the end of 2019. However, this changed from 1 January 2020, as there is now a legal entitlement to care leave in companies with more than five employees.

Financial subsidies for '24-hour care' (*24-Stunden-Betreuung*) may be granted so that people in need for LTC are looked after in their homes by privately-hired nursing staff. The person to be looked after must have been granted LTC cash benefit of at least level 3 and above and

[736] For details see https://www.sozialministerium.at/Themen/Pflege/Pflegegeld.html (accessed 30.04.2020)
[737] A follow-up assessment may take place in case of a change of the requirements/the health status of the person in need of care. LTC recipients or their relatives can apply for a follow-up assessment in case of rising LTC requirements. On the other hand, they also have to report substantial health improvements, which could cause a reduction or a removal of LTC cash benefit.
[738] Care leave may also take the form 'part-time care leave', where the usual working time may get reduced to a minimum of 10 hours per week.
[739] For more details see https://broschuerenservice.sozialministerium.at/Home/Download?publicationId=288 (accessed 19.04.2020)
[740] In the case of people to be looked after suffering from dementia and minors to be looked after, level 1 is sufficient.
[741] In 2018, in total 947 persons were granted *Pflegekarenzgeld* at monthly average (BMASGK 2019, p. 147).

their personal income may not exceed EUR 2500 net per month for a single person, whereby LTC cash benefit is not counted as part of the income.[742] The financial subsidy in the case of self-employed caregivers amounts to EUR 275 per month per caregiver, with a maximum subsidy of EUR 550 (this corresponds to two caregivers). So that the caregivers get employed via a normal working contract, the subsidy amounts to EUR 550 per month per carer/nurse, with a maximum monthly subsidy of EUR 1100 (this corresponds to two caregivers). Around 24,700 such financial subsidies were granted on average per month in 2018, with a total yearly costs amounting to EUR 158.4 million.[743]

In Austria, no legal entitlement exists regarding availability and access to formal home care services and/or to residential care. However, in all federal provinces there is a legal entitlement for (socially adjusted) public co-financing of mobile and residential LTC (see below sections 2.1).

## 1.4 Supply of services

A wide variety of LTC services are available in Austria. Residential care is delivered in institutions specifically put in place for this purpose, such as nursing homes and supervised residential communities for older people (so-called 'alternative dwellings'). Short-term residential care includes offers of temporary care in nursing homes for up to three months, in part to relieve relatives who offer care at home or to provide an alternative during their temporary absence (on leave or because of illness). Semi-residential care offers whole-day or at least half-day support for people in need of care who do not live in facilities providing residential care. It is usually provided in institutions specifically set up for this purpose. Services delivered to people in need of LTC living in private homes include care and social support, as well as palliative care and other guidance and counselling (e.g. support in financial management). This type of support includes home help and home nursing, where trained carers and nurses visit people in need of care once or twice a day at home to perform specific tasks (depending on the actual need) or to deliver meals ('meals on wheels').

According to information provided by the LTC-Service-Database of Statistics Austria[744] about 153,500 people received formal home care services in 2018 and around 8200 people received day-care services. On the other hand, 95,100 people permanently lived in retirement and nursing homes, and about 3500 in so-called alternative dwellings. Another 9900 people received short-term residential care (with a duration of up to three months).[745] Calculated according to the headcount of people receiving services the relation between home care plus day care versus permanent plus short-term residential care is about 6 to 4. To get an idea of the coverage of these different services and about their regional distribution, one can compare the number of recipients of different services to the number of recipients of LTC cash

[742] The income threshold gets increased by EUR 400 for every person in the household entitled to maintenance.
[743] BMASGK, 2019, p. 38.
[744] Note: This data source covers LTC services co-financed by funds from Social Assistance and Minimum Income schemes.
[745] Statistik Austria, *Pflegedienstleistungsstatistik*, prepared 10.12.2019. http://www.statistik.at/wcm/idc/idcplg?IdcService=GET_NATIVE_FILE and RevisionSelectionMethod=LatestReleased and dDocName=061948 (accessed 18.04.2020) and own calculations.

benefits, whereby the latter serves as a proxy for the potential number of clients.[746] Overall, the coverage rate is highest for home care services (33.5 %), followed by permanent residential services (20.7 %). The other services (day care, short-term residential services) show a much lower prevalence, in all cases not exceeding 4 %. Furthermore, especially regarding permanent residential care a substantial differentiation according to federal provinces is evident, with coverage rates varying between 14.7 % in Burgenland and 26.1 % in Tyrol.[747]

In the first instance, the federal provinces are responsible for planning and financing these services. However, actual implementation takes place in cooperation with municipalities, not-for-profit organisations of the so-called intermediary sector (i.e. social non-governmental organisations of various types and orders), and, to a lesser degree, also in cooperation with for-profit providers. No recent data is available on the concrete market share of different types of settings. However, it appears that formal home care is almost exclusively provided by private not for-profit organisations, and 'meals on wheels' by municipalities.[748] Permanent residential care is, depending on federal provinces, at first instance organised by municipalities, and to a lesser degree by private not for-profit organisations. However, especially in the federal provinces Burgenland and Styria, the majority of all residential care facilities are run by private providers, and in Styria, a high proportion of residential facilities exist which are run by private for-profit providers (amounting to about 53 %).[749]

According to the LTC-Service-Database of Statistics Austria[750] the professional staff engaged in the above-mentioned services at the end of the year 2018 amounted to around 35,400 full-time equivalents for residential services and around 12,550 full-time equivalents in the area of home care.[751] The total number of personnel primarily engaged in the remaining other services amounted to about 1300 full-time equivalents. At the end of 2018, around 88 % of the professional staff (headcount) engaged in these services were women.[752]

As already detailed above (see Section 1.2) the vast majority – about 85 % - of all people in need of LTC live in private homes (Nagl-Cupal et al., 2018). Of these, around 55 % receive informal care only and about 45 % a mix of informal and formal care. According to recent estimations up to 800,000 people[753] are likely to be engaged in informal care for recipients of LTC cash benefit living at home (Nagl-Cupal et al., 2018, 169ff.). This equals on average two informal carers per recipient of LTC cash benefit living at home.

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[746] These 'coverage rates' depict the number of recipients of different types of services in % of the total number of recipients of LTC cash benefits.
[747] Own calculations based on: Statistik Austria, *Pflegedienstleistungsstatistik*, prepared 10.12.2019. http://www.statistik.at/wcm/idc/idcplg?IdcService=GET_NATIVE_FILE and RevisionSelectionMethod=LatestReleased and dDocName=061948 (accessed 18.04.2020)
[748] See Grossmann/Schuster, 2017, p. 8.
[749] See Rechnungshof, 2020, pp. 31-32.
[750] Note: This data source covers LTC services co-financed by funds from Social Assistance and Minimum Income schemes.
[751] For details according to federal provinces see http://www.statistik.at/wcm/idc/idcplg?IdcService=GET_NATIVE_FILE and RevisionSelectionMethod=LatestReleased and dDocName=080309 (accessed 20.04.2020)
[752] http://www.statistik.at/wcm/idc/idcplg?IdcService=GET_NATIVE_FILE and RevisionSelectionMethod=LatestReleased and dDocName=122296 (accessed 20.04.2020)
[753] To put this number into context: 800, 000 people equal 18.5 % of the total workforce, which at yearly average amounted to 4,350,000 people in 2019. http://www.statistik.at/wcm/idc/idcplg?IdcService=GET_NATIVE_FILE and RevisionSelectionMethod=LatestReleased and dDocName=062875 (accessed 01.06.2020)

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

LTC cash benefits are based on legal entitlement. They are not means tested in terms of personal or family income or assets, and in principle are granted as a universal benefit, according to seven different levels of individual care requirements/the health status of the person in need of care. However, the LTC cash benefit only covers a fraction of the costs of residential care. To give an example: For a person with need of LTC equal to level 4 of the LTC cash benefit, the daily costs for residential care currently amount to between EUR 95 and EUR 140, depending on the federal province (Rechnungshof, 2020, p. 91). This results in monthly costs between EUR 2850 and EUR 4200. However, the LTC cash benefit at level 4 amounts to only EUR 689.8 per month.[754]

The same applies, especially in cases of extensive need of care, to the costs arising if all support is purchased within formal home care. To give an example: A person with a LTC cash benefit of level 4 is supposed to have need for care amounting to at least 160 hours per month. The home care costs to be covered per hour by people in need of LTC on average[755] amounts to between EUR 11 to EUR 23, depending on the federal province (Rechnungshof (2020, p. 140). 160 hours care received via formal home care would result in monthly costs of between EUR 1760 and EUR 3680. However, the LTC cash benefit at level 4 amounts to only EUR 689.8 per month. These potential challenges apply irrespective of the fact that these hourly rates are co-financed by the federal provinces. The total hourly costs for outpatient care, i.e. including co-financing by the federal provinces, on average[756] amount to between EUR 30 and EUR 60, depending on the federal province (Rechnungshof, 2020, p. 140).

Overall, the issue of affordability arises because access to LTC services is, in principle, not free of charge. These are only fully financed by the federal provinces if the LTC services cannot be financed via a person's own income. This is done within the social assistance/minimum income schemes of the federal provinces. Here, means testing applies, where all kinds of personal income, including LTC cash benefits, are taken into account. Until recently, in the case of residential LTC, most federal provinces also had means testing covering the assets of people in need of LTC; those assets normally had to be realised before the costs were covered by the public (*Pflegeregress*).[757] However, a recently voted Constitutional Provision (amending section §330a of the General Law on Social Insurance/ASVG), effective from January 2018, prohibits recourse to the assets of people living in LTC facilities, as well as recourse to the assets of their relatives, heirs or gift recipients.

[754] https://www.oesterreich.gv.at/themen/soziales/pflege/4/Seite.360516.html (accessed 01.06.2020)
[755] The federal provinces apply different models of socially adjusted private co-payments for mobile LTC. The numbers indicated here are average co-payments across different levels of personal income or other parameters of social adjusting (for more details see Rechnungshof 2020, 140ff.).
[756] Different total hourly costs apply for different types of LTC services (see Rechnungshof 2020, 137).
[757] This – inter alia – meant that dwellings could be subject to a lien within the land registry in favour of the federal province (normally after having received services financed via Social Assistance/Minimum Income for six months).

Overall, these regulations encourage a considerable part of LTC to be covered in an informal way, as many people are reluctant to apply for social assistance/minimum income, where only a small personal budget remains freely available for disposal, and where until recently assets had to be realised in the case of residential care.

Some empirical evidence is available regarding the perceived problems of financial feasibility of formal home care services. According to a survey conducted by Nagl-Cupal et al. (2018), 11 % of all households with recipients of LTC cash benefits reported that they were 'scarcely sufficient' to cover the costs of necessary formal home care services, 45 % said they were 'partly sufficient', 29 % said they were 'largely sufficient', and 15 % reported that they were 'fully sufficient' (ibid, 42). Hereby, it should be noted that some of the LTC services in all of these households are provided in an informal way. Some evidence on this issue is also available from an EU-SILC ad-hoc module in 2016. According to this data source, 2.2 % of all people in Austria reported that they used professional homecare services (on average in the EU-27 this applied to 1.9 % of all people).[758] In Austria, the main reasons for not using professional homecare services[759] were: 52.5 % 'no need' (EU-27: 33.7 %), 25.6 % 'financial reason' (EU-27: 35.7 %), 8.9 % 'refused by the person needing such services' (EU-27: 5 %), 7.2 % 'other reason' (EU-27: 13.7 %), 5.6 % 'no care services available' (EU-27: 9.7 %) and 0.3 % 'quality of the services available not satisfactory' (EU-27: 2.1 %). For households with an income below 60 % of the national equivalised income, financial reasons are even more important for not using professional homecare services. For such households, 47.9 % in Austria report that financial issues are the main reason for not using professional homecare services (EU-27: 45.5 %), and 39.7 % report that they have 'non need' (EU-27: 29.3 %). These indicators and data do not allow for a more detailed assessment of affordability of LTC services in Austria.[760] Still, they point towards the fact that affordability of formal care is an issue, which contributes to the continuing substantial importance of informal care.[761]

## 2.2 Quality

In Austria, there is currently[762] no clearly defined and integrated quality framework, covering the different sectors of LTC. The above mentioned '15a agreement'[763] on LTC between the Federal Republic and the federal provinces only defines rather general quality criteria and leaves considerable room for interpretation. On the subnational level, the federal provinces enacted more detailed regulation to promote the quality of LTC services. The main instruments are the federal provinces' legislations concerning the minimum income schemes, nursing home acts (five federal provinces) or nursing home decrees (four federal provinces), and specific directives on the organisation and implementation of different LTC services.

[758] EU-SILC 2016, Eurostat Database, indicator [ilc_ats13].
[759] EU-SILC 2016, Eurostat Database, indicator [ilc_ats15].
[760] See for other countries/regions: Muir, T., 'Measuring social protection for long-term care', *OECD Health Working Papers*, No 93, OECD Publishing, Paris, 2017.
[761] See for a discussion e.g.: Mairhuber, I./K. Sardadvar, 'Erwerbstätige pflegende Angehörige in Österreich: Herausforderungen im Alltag und für die Politik - Projekt-Teilbericht: Policy-Analyse und politische Empfehlungen', *FORBA-Forschungsbericht*, Vienna, 2017.
[762] April 2020.
[763] BGBl. Nr. 866/1993. http://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen and Gesetzesnummer=10001280 (accessed 16.04.2020)

Same as the quality criteria of the 15a agreement, these regulations address the structural and procedural aspects of LTC quality, and usually do not give much emphasis to outcome-related aspects. [764] When compared between federal provinces, the related regulations show a substantial differentiation between federal provinces regarding content and level of detail.[765] Regarding nursing homes, they usually deal with building and infrastructural issues, residents' rights, minimum number and qualification of staff and duties of documentation. Regarding outpatient services, the main areas of regulation are qualifications of staff, rules regarding the existence of quality documentation instruments and/or of quality management tools. Different types of outcome-related indicators appear to be used within internal documentation of the service providers, and no general instruments are in place to be used by all of them. Furthermore, no instruments explicitly aimed at an independent inspection to assess the quality of LTC providers appears to be in place (but see below on '24-hour care' at home). On this, background systematic monitoring of outcomes generally appears to be underdeveloped in formal LTC and substantial differences exist between federal provinces regarding input- and process-related aspects of quality assurance (for a discussion see also Rechnungshof 2020, 99ff.).

Quality is also an issue in informal care. A specific, additional governance implemented by an institution of the Federal Republic is worth mentioning here. Within the so-called 'home visit programme'[766], organised by the Federal Ministry for Social Affairs, certified healthcare and nursing professionals visit the homes of first-time recipients of LTC cash benefits to inform and advise all those involved in the specific care situation, to ensure the quality of home care throughout Austria. Based on these home visits, certified healthcare and nursing professionals grade the quality of care according to a modified ASCOT methodology (Adult Social Care Outcomes Toolkit)[767]. This instrument evidently emphasises outcome-related aspects of LTC. These 'home visits' are not compulsory, i.e. potential clients may refuse to participate. However, this does not apply in the case of an application for financial subsidies for '24-hour care' at home (so called live-in carers, see above section 1.3). In this case, a home visit is obligatory and may not be refused.[768]

One other point worth mentioning in this context are different attempts for quality certification. Regarding nursing homes and homes for older people, there exists a so-called 'National Quality Certificate' (*Nationales Qualitätszertifikat; NQZ*). This programme was initiated by the Federal Ministry of Social Affairs and has been in place since 2012.[769] The NQZ deals with process- and outcome-related aspects of LTC quality and may be granted

[764] For the distinction between structure, process and outcome in evaluating quality of health care according to the so-called 'Donabedian model' see Donabedian, A., 'The definition of quality and approaches to its assessment Exploration in quality assessment and monitoring', Vol. 1, *Health Administration Press*, Ann Arbor, 1980.
[765] See BMASGK (2019) and Rechnungshof (2020) for details. See also: Dimmel, N., *Qualität und Qualitätssicherung im Österreichischen Recht der Sozialdienstleistungen - Studie zu praxisorientierten Standards 'vergabefremder Kriterien'*, Salzburg, 2015. https://www.dabei-austria.at/download/?id=320 (accessed 20.04.2020)
[766] For details and results see https://www.svs.at/cdscontent/?contentid=10007.816614 (accessed 20.04.2020)
[767] See https://www.pssru.ac.uk/ascot/ (accessed 20.04.2020); see also: Trukeschitz, B., 'Worauf es letztlich ankommt. Ergebnisqualität in der Langzeitpflege und -betreuung' [What matters in the end. Quality of results in long-term care and assistance], *Kurswechsel*, 4/2011, pp. 22-35. http://epub.wu.ac.at/5297/1/Worauf-es-letztlich-ankommt.pdf (accessed 20.04.2020)
[768] See https://www.sozialministerium.at/Themen/Pflege/Qualitaetssicherung.html (accessed 20.04.2020)
[769] For details see https://www.nqz-austria.at/das-nqz/ (accessed 20.09.2019).

after an in-depth evaluation, usually taking about eight months. Currently, about 55 out of a total of 850 nursing homes and homes for older people are certified according to the NQZ. Since 2019, a quality certification instrument also exists in the area of '24-hour care' at home.[770] Again, this programme has been initiated by the Federal Ministry of Social Affairs. Currently only 16 out of a total of more than 800 registered agencies recruiting personnel for '24-hour care' have been certified according to this system. Certification may help to mitigate problems of asymmetric information regarding LTC, where clients and their relatives often have substantial problems to assess quality prior to using it, which furthermore may also be difficult afterwards too. The – up to now – rather low number of certified service providers evidently very much limits the actual impact of these certification schemes.

## 2.3 Employment (workforce and informal carers)

GÖG (2019) recently presented an analysis of the structure of the LTC workforce in formal care and projections about likely future staffing requirements. In 2017, nursing staff (of different qualification levels) according to registry data amounted to around 33,200 full-time equivalents regarding residential and day care, and to around 11,700 full-time equivalents regarding formal home care. As a substantial share of nurses and carers work part-time, this translates to a workforce of about 41,100 people in residential LTC, and to about 18,000 people in formal home care. This translates to around 3.64 LTC workers per 100 individuals aged 65+.[771] More than 85 % of these are women. According to projections by the GÖG (base case scenario) by 2030 full-time equivalents will have to rise to 44,000 in residential and day care, and to 15,100 in formal home care. At the same time about 20,000 carers and nurses (full-time equivalents) will retire by 2030, resulting in the need to recruit around 34,200 carers and nurses (full-time equivalents) by 2030.

This appears to be a substantial challenge, as the sector is known for high levels of strain, high workload, irregular working hours[772] and comparatively low levels of income.[773] These are all obstacles to attracting new applicants and might push educated carers to look for other employment opportunities. Therefore, the profession of carer/nurse features on the so-called shortage occupation list.[774]

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[770] See https://oeqz.at/ (accessed 30.04.2020)

[771] The OECD indicates a somewhat higher number of LTC workers per 100 individuals in the age 65+, amounting to 4.1 both in 2011 and 2016. This may be caused by a different data source, which is the Labour Force Survey for the OECD data. On average in the EU, the OECD indicates 3.8 LTC workers per 100 individuals in the age 65+ (see Section 5, 'Background statistics'); for more details see OECD (2019). Ensuring an Adequate Long-Term Care Workforce, Final Report, Paris.

[772] See OECD, *Ensuring an Adequate Long-Term Care Workforce, Final Report*, OECD Publishing, Paris, 2019. However, the OECD (2019, p. 46) also reports that perceived recruitment challenges are lower in Austria than in many other EU Member States.

[773] The average yearly gross income of permanently full-time employed women amounted to about EUR 36,800 in 2017. For female 'care assistants' (ISCO 5321) it amounted to EUR 26,250; source: Rechnungshof, *Allgemeiner Einkommensbericht 2018*, Vienna, 2018, p. 124. https://www.rechnungshof.gv.at/rh/home/home_1/home_1/Einkommensbericht_2018.pdf (accessed 03.06.2020) See also results from *Work and Life Quality in New and Growing Jobs Project – Care profession*. https://cordis.europa.eu/result/rcn/56349_en.html (accessed 21.04.2020) and https://awblog.at/wo-in-gesundheitsberufen-der-schuh-drueckt/ (accessed 21.04.2020) See also: Bauer, G., Rodrigues, R. and Leichsenring, K., *Arbeitsbedingungen in der Langzeitpflege aus Sicht der Beschäftigten in Österreich. Eine Untersuchung auf Basis der internationalen NORDCARE-Befragung*, Vienna, 2018. https://www.euro.centre.org/downloads/detail/3288/1 (accessed 21.04.2020)

[774] See https://www.migration.gv.at/de/formen-der-zuwanderung/dauerhafte-zuwanderung/bundesweite-mangelberufe/ (accessed 20.04.2020)

What should additionally be stressed in this context is the phenomenon of '24-hour care' (*24-Stunden-Betreuung*), already addressed above. About 25,000 people in need of LTC are currently looked after by about 50,000 privately hired carers/nurses at home (so called live-in carers).[775] Most of them are temporary migrant carers from Eastern EU Member States like Slovakia, Romania and Bulgaria. '24-hour care' partly serves as a substitute for (more costly) residential care. In most cases, these carers are self-employed and one person in need for LTC is alternately looked after by two carers, each of them staying in Austria for usually two or three weeks, and then being replaced by the other. Overall, their working conditions appear to be rather problematic, inter alia in terms of income, working time and physical and psychological stress.[776] At the same time, it is questionable if this model is sustainable given that such arrangements could diminish in future when living standards rise in these EU Member States. This – in turn – would imply a steep increase in demand for carers and nurses in formal LTC, and/or it would further increase the pressure on family members to provide LTC on an informal basis.

Different measures have been taken in Austria over the last decade in order to increase the availability of carers of different qualification levels. In 2016, the educational system for carers and nurses was reformed, with the goal to offer different options of qualification levels, to attract more new applicants.[777] The federal provinces, partly in co-operation with the public employment service (PES), offer different models of financial subsidies while people are in education for related professions. Another measure is the substantial expansion of counselling services for the validation/recognition of qualifications acquired in other countries, which are also available for people in the caring professions.[778]

Regarding relatives providing informal care, it should be mentioned that short-term residential care and day care, available to different degree in all federal provinces, may also offer respite care. Furthermore, a specific financial subsidy is available to caring relatives in need of short-term replacement by formal home-care. This subsidy may amount to between EUR 1200 and EUR 2300, depending on the level of the LTC benefit of the person in need of care.[779] Furthermore different counselling services and also training/upskilling measures are available and offered by different institutions.[780] Still, it appears that informal caregivers in many cases face different types of very substantial stresses and strains.[781] Furthermore, providing informal care often implies a termination of gainful employment or a reduction of working time (see below section 2.4).

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[775] BMASGK, *Österreichischer Pflegevorsorgebericht 2018*, 2019, Vienna. https://broschuerenservice.sozialministerium.at/Home/Download?publicationId=719 (accessed 30.04.2020)
[776] See e.g. Schmidt, A. and Leichsenring, K., 'Der österreichische Weg der 24-Stunden-Betreuung und seine Wirkung auf Qualität und Qualitätssicherung', *Soziale Sicherheit*, 1/2016, 2016, pp. 15-21.
[777] For more details see https://www.parlament.gv.at/PAKT/PR/JAHR_2016/PK0820/ (accessed 30.04.2020)
[778] See https://www.anlaufstelle-anerkennung.at/ (accessed 30.04.2020)
[779] See https://sozialministeriumservice.at/Finanzielles/Pflegeunterstuetzungen/Pflegende_Angehoerige/Unterstuetzung_fuer_pflegende_Angehoerige.de.html (accessed 02.06.2020)
[780] See e.g.: https://www.roteskreuz.at/pflege-betreuung/kurse/pflegende-angehoerige/ or https://www.caritas-pflege.at/angehoerige/kurse-vortraege/ (accessed 02.06.2020)
[781] For details see Nagl-Cupal et al. (2018, p. 77ff).

## 2.4 Financial sustainability

According to calculations provided in the 2021 Ageing Report[782] public spending for LTC in Austria amounted to 1.8 % of GDP in 2019 (EU-27: 1.7 %).[783] According to then AWG reference scenario, these costs in Austria will rise to 2.2 % of GDP in 2030 (EU-27: 1.9 %) and then further to 3.2 % in 2050 (EU-27: 2.5 %). According to the AWG risk scenario, which implies higher coverage rates by formal care, LTC expenditure in Austria would rise to 2.3 % of GDP in 2030 (EU-27: 2.1 %) and to 3.7 % in 2050 (EU-27: 3.4 %).[784] In this context, it should be taken into account that the reference scenario shows lower direct LTC costs, but that it is likely to come with higher opportunity costs, due in part to informal carers being forced to reduce or stop formal employment, which also implies a reduction of income tax and social security contributions. Data from a recent survey indicates that around 53 % of all informal carers in Austria were old-age pensioners, whereas the remaining 47 % would theoretically have been available to the labour market. Out of the latter, around 23 % indicated that they had left employment due to informal care responsibilities and about 26 % had reduced their working time.[785]

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

The Austrian LTC described and analysed above addresses people in need of LTC irrespective of their age. No major specific challenges and/or prominent debates exist around other age groups.

# 3 REFORM OBJECTIVES AND TRENDS

Austria has repeatedly received a Country Specific Recommendation addressing LTC. Within the 2019/2020 European Semester the Council, it recommends that Austria should take action to

'Ensure the sustainability of the health, LTC, and pension systems, including by adjusting the statutory retirement age in view of expected gains in life expectancy. Simplify and rationalise fiscal relations and responsibilities across layers of government and align financing and spending responsibilities.'

In the area of LTC, this would call for a rather comprehensive redesign of the system in place, including more co-ordination of measures decided by federal provinces and a reform of financing instruments.

[782] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.
[783] See also: Section 5, 'Background statistics'. Note: This data does not only address the 'health-related' part of LTC expenditure, as covered category HC.3 of the OECD system of health accounts, but also an estimation for the 'social-related' part of LTC expenditure, as covered in category HC.R.1 of the OECD system of health accounts. HC.3 alone recently amounted to 1.5 % of GDP (Source: OECD Database; https://stats.oecd.org/).
[784] Overall, the statement that public spending for LTC is likely to increase substantially in the future is common to different projections on this issue, available from different sources. For a recent national projection. See Grossmann/Schuster (2017).
[785] Own estimates based on data provided by Nagl-Cupal et al., 2018, 47 ff.

However, no major structural reforms, leading to a comprehensive restructuring of the system, has taken place in LTC since 1 January 2017. Still, some agreed measures are worth mentioning.

The one with the potentially largest impact is the decision to prohibit recourse to the assets of people living in residential LTC facilities (*so-called Pflegeregress*). This was decided on 29 June 2017 by the Austrian Parliament via a Constitutional Provision and came into effect from 1 January 2018.[786] Federal provinces are now prohibited to take recourse to the assets of people living in residential LTC facilities, as well as to take recourse to the assets of their relatives, heirs or gift-recipients, to cover costs for LTC otherwise to be borne by social assistance. This may have a substantial impact, incentivising more people to opt for residential care, as such a decision previously often resulted in the LTC recipient losing all of their assets. At the same time, the Federal Republic agreed to compensate the federal provinces for their financial losses resulting from the prohibition of recourse to assets. For the year 2018, this compensation amounted to EUR 295.5 million, and similar sums are expected for subsequent years (subject to yearly evaluation).

One other important measure was decided in the Austrian Parliament at the beginning of July 2019, when several decisions were taken by changing majorities after a vote of non-confidence against the earlier coalition government of the Austrian Peoples' Party (ÖVP) and Austrian Freedom Party (FPÖ). This decision, effective from January 2020, enacts a yearly indexation of LTC cash benefits. This is a major change, as LTC cash benefits were previously indexed very infrequently, which implies a substantial devaluation of these benefits in the mid-term.

Another measure, decided in Parliament just before the (early) national elections of September 2019, was the introduction of a legal entitlement to care leave, which now applies in companies with more than five employees, effective from 1 January 2020. Until the end of 2019, there was no legal entitlement to care leave, i.e. the employee and the employer had to mutually agree on it, which resulted in a rather low take-up.

No comprehensive evaluation of the effects of the COVID-19 pandemic on the different strands of the LTC system has been undertaken in Austria up to now. Evidently, LTC has been affected by the prevention measures decided by the Austrian Federal Government, implying inter alia a ban on visitors in residential care facilities etc. At the same time formal home care services continued to be available without interruption. Problems arose especially around '24-hour care' at home because of travel bans. Here, to some extent, specific initiatives were taken, like e.g. organising some transfer flights and corridor trains to and from Romania in order to guarantee some limited exchange of carers.[787] Apart from that, no more structural measures were announced or decided by the end of May 2020 because of the COVID-19 pandemic.

[786] See https://www.parlament.gv.at/PAKT/PR/JAHR_2017/PK0838/index.shtml (accessed 30.04.2020)
[787] Usually, carers providing '24 hours care' operate in a regular cycle of working two or three weeks in Austria and staying in their original home countries for two or three weeks etc. On the transfer fights and corridor trains see e.g.: https://noe.orf.at/stories/3048561/ and https://noe.orf.at/stories/3048055/ (accessed 04.06.2020)

***Planned reforms and on-going legislative process and debates***

*A new coalition government of ÖVP and the Greens took office in Austria in January 2020. The government programme[788] announced a comprehensive reform of LTC, which also is planned to encompass nation-wide planning and co-ordination and a reform regarding structures of financing. Some details of concrete plans mentioned in the government programme point to the fact that it is not envisaged to change the basic design of the LTC system, comprising of LTC cash benefits being the responsibility of the Federal Republic and social services being the responsibility of the federal provinces. So, overall, the signals provided by the government programme are somewhat contradictory regarding the actual scope of the envisaged reform, with details unclear at the time of writing.*

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The Austrian LTC system faces a number of evident challenges and needs for improvement.

First, the existing legal and governance framework led to a situation of split responsibilities and competencies (between the Federal Republic and the federal provinces), which comes with tendencies of problem- and cost-shifting.[789] Furthermore, due to a lack of nationwide co-ordination, very substantial differentiations between the different federal provinces developed regarding coverage rates by different LTC systems, concerning quality standards and instruments for quality assurance, in the area of needs assessments and future planning and also concerning actual costs to be covered from private resources. So, a reform of the existing legal and governance framework should aim at a clarification of competencies and accountability, and it should strengthen co-ordination between different sectors. Amongst other things, emphasis would have to be given to a nationwide definition and implementation of quality standards of LTC.

The model of '24-hour care' at home, provided by temporary migrant carers from eastern EU Member States, does not appear to be sustainable from a mid-term perspective. At the same time, its existence indicates deficits in other areas of residential care and formal home care.

One of the main challenges is the one of affordability. The existing system design and structures of financing – in case of substantial need for LTC – (apart from '24-hour care') in principle only allow for two options for those in need of LTC and their families. One is to opt for residential care, where costs are usually covered by social assistance/minimum income, but where people in need of LTC also have to contribute with all their personal income (with the exemption of a small amount of 'pocket money'). The other option is informal care provided by family members, in combination with some limited formal home care services purchased with financial resources coming from LTC cash benefits and/or other personal income (like pension benefits, savings, income of other family members).

[788] See Republik Österreich, *Aus Verantwortung für Österreich. Regierungsprogramm 2020–2024*, Vienna, 2020. https://www.bundeskanzleramt.gv.at/dam/jcr:7b9e6755-2115-440c-b2ec-cbf64a931aa8/RegProgramm-lang.pdf (accessed 21.04.2020)

[789] See also: Rechnungshof, 2020.

To address this problem, the availability and especially the affordability of formal home care would have to be improved further. Such a 'defamilialisation' of care work would come with higher public costs and increased numbers of professional carers/nurses. On the other hand, it would by all likelihood be more cost efficient than a model where residential care gets further expanded, and it would not undermine employment opportunities of informally caring relatives, as is currently the case. At the same time this would imply a major shift from a model with universal entitlement to cash benefits, to a model with universal entitlement to in-kind benefits.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 8.3 | 8.9 | 9.1 | 9.3 |
| Old-age dependency ratio, 2019 | | 25.4 | 28.2 | 36.6 | 47.2 |
| Population 65+ (in millions), 2019 | Total | 1.4 | 1.7 | 2.1 | 2.6 |
| | Women | 0.8 | 0.9 | 1.2 | 1.4 |
| | Men | 0.6 | 0.7 | 0.9 | 1.2 |
| Share of 65+ in population (%), 2019 | | 17.1 | 18.8 | 23.0 | 27.7 |
| Share of 75+ in population (%), 2019 | | 7.9 | 9.4 | 10.8 | 16.3 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.8* | 20.3 | | |
| | Women | 21.4* | 21.7 | 22.9 | 24.8 |
| | Men | 17.9* | 18.7 | 19.8 | 21.8 |
| Healthy life years at the age of 65, 2018 | Total | 8.1* | 7.4 | | |
| | Women | 7.9* | 7.4 | | |
| | Men | 8.5* | 7.5 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 781.2 | 870.9 | 1,029.6 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 415.4 | 520.7 | 710.3 |
| | Women | | 252.8 | 308.6 | 419.6 |
| | Men | | 162.6 | 212.2 | 290.7 |
| Share of potential dependants in total population (%), 2019 | | | 8.8 | 9.5 | 11.0 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 16.3 | 16.0 | 17.7 |
| Share of population 65+ in need of LTC** (%), 2019* | | 17.5 | 27.0 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 3.8 | 3.9 | 4.9 |
| Share of population 65+ receiving care at home (%), 2019 | | | 4.8 | 4.8 | 5.9 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 21.6 | 21.7 | 26.4 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 34.6 | 35.2 | 39.5 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 87.6 | 88.7 | 96.4 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 43.6 | 32.4 | | |
| | Women | 48.4 | 33.8 | | |
| | Men | 30.4 | 29.5 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 5.6 | 9.8 | | |
| | Women | 6.6 | 12.6 | | |
| | Men | 4.3 | 6.3 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 25.6 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 5.6 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 777.7 | 865.1 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 4.1 | 4.1 | | |
| | % Women | | 88.2 | | |
| Share of population providing informal care (%), 2016 | Total | | 8.1 | | |
| | Women | | 9.6 | | |
| | Men | | 6.4 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 19.0 | | |
| | Women | | 20.4 | | |
| | Men | | 16.9 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.4 | 1.8 | 2.2 | 3.2 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.4 | 1.8 | 2.3 | 3.7 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 27.7 | 49.1 | 50.3 | 52.4 |
| Public spending on home care as % of total LTC public spending, 2019 | 10.0 | 9.9 | 9.9 | 9.8 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 62.3 | 41.0 | 39.8 | 37.7 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 1.2 | 1.1 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.4 | 0.4 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# POLAND

### *Highlights*

- *An increase in life-expectancy combined with the low total fertility rate (TFR is equal 1.48 to in 2017) contribute to the population ageing. The proportion of people aged 65+ in the population was 17.7 % in 2019, but is foreseen to reach 22.7 % in 2030. The proportion of people aged 80+ was 4.4 % in 2019 and is projected to grow to 5.7 % in 2030.*
- *Long-term care (LTC) benefits and services are available in the health and social sector, targeting different population groups (older people, people with disabilities, those incapable of living independently). Homecare services reached 3.4 % of the 65+ population and residential care 2.7 % of the 65+ population in 2019. Cash benefits reached 37.2 % of the population older than 65 in 2019.*
- *The total public LTC expenditure was lower than in many other EU-27[790] countries, constituting 0.8 % of GDP in 2019. Due to the ageing population, it is estimated to increase to 1.7 % of GDP in 2050 (reference scenario) or to 3.1 % of GDP (risk scenario).*
- *LTC employment is low compared to other EU-27 countries – 0.5 LTC workers per 100 older people (EU-27 average: 3.8, 2016 data). There are inequalities in working conditions and wages between the healthcare and the social sector. The number of carers is increasing, but ageing of medical and nursing staff will put additional pressure on ensuring adequate care.*
- *Process-oriented measures in assuring care quality are present in both sectors of care, and particularly in residential services. With the developing private care sector, performance monitoring and quality measures in private institutions are lacking.*
- *The government introduced several programmes aimed at increasing access to care services for older people, investing in community care and supporting people incapable of independent living and those vulnerable to poverty with income transfers and introducing respite care solutions. The sustainability of the adopted measures should be strengthened and closer coordination of health and social functions in LTC is needed.*

[790] EU-27 refers to the current 27 Member States of the European Union.

# 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

## 1.1 Demographic trends

The LTC system in Poland is expected to face increasing pressure in the coming years due especially to the ageing population that is likely to lead to higher demand and reduced financial resources deriving from taxes to ensure future supply of LTC. There is about 6.7 million people aged 65+ in Poland and the absolute number of older people increased between 2008 and 2019 by 1.6 million people[791]. In 2019, the proportion of people aged 65+ in the population is 17.7 %, the proportion of people aged 75+ is 7.2 % and those aged 80+ is 4.4 %. There are regional discrepancies in the share of older people (aged 65+) with the highest share in Iódzkie (19.5 %) and Świętokrzyskie (19.0 %) and the lowest in Wielkopolskie (16.3 %) and Pomorskie (16.4 %)[792]. Demographic projections show a rapid increase in the number of older people, changing the structure of the population. The share of people aged 65+ in the population will rise to 22.7 % in 2030 and to 30.1 % in 2050. The proportion of people aged 80+ will, reach 5.7 % in 2030 and 9.7 % in 2050. The Old-age dependency ratio is projected to increase from 26.4 % in 2019 to 35.6 % in 2030 and 52.2 % in 2050.
The life expectancy of older people at the age of 65 has increased over the past decade to 20.4 years for women and 16.1 years for men (2019 data), but only about half of this time is spent in good health and free from disabilities (8.8 years for women/8.2 years for men).

There are no official public estimates of the number of older people in need of care. European Health Interview Survey (EHIS) data show that 35 % of people aged 65+ face severe and 24.3 % moderate difficulties in personal care or household care activities. Educational inequalities persist with severe difficulties more frequently seen in lower educated strata (47.3 %)[793]. There were about 2.556 million dependent people in Poland in 2019 (see Section 5). The overall share of potential dependants in the population is foreseen to grow from 6.7 % in 2019 to 7.6 % in 2030 and 9.2 % in 2050.

The COVID-19 pandemic hit older people particularly hard. Out of the total number of 5542 deaths reported by 20 October 2020[794], 58.05 % were people aged 65+ but their share of confirmed cases only represented 15.65 %[795]. Medical doctors and nurses tend to work in different medical units (hospital, care facility etc.), and this became one of the causes of spreading COVID-19 in social welfare homes and nursing facilities across the country[796/797].

[791] All data used in the text come from Section 5 'Background statistics' unless explicitly stated otherwise.
[792] GUS, *Demographic Yearbook of Poland*, 2019. https://stat.gov.pl/obszary-tematyczne/roczniki-statystyczne/roczniki-statystyczne/rocznik-demograficzny-2019,3,13.html
[793] EHIS [[hlth_ehis_tae].
[794] The first case of COVID-19 in Poland was reported in the first week of March 2020.
[795] Calculation based on the data published by the Ministry of Health.
[796] http://www.dps.pl/koronawirus/
[797] According to latest data for social LTC sector (as of 1 October 2020) 2 712 residents (regardless of age) in 115 residential social homes all together were reported as infected with SARS-CoV-2 (890 actually infected, 1 617 recoveries, 205 deaths). According to latest data for LTC in healthcare sector (as of 15 September 2020) 965 patients (regardless of age) in 121 chronic care homes and nursing homes all together were reported as infected with SARS-CoV-2 (609 recoveries, 163 deaths). Additionally, 66 patients in 13 hospices all together were also infected (44 recoveries, 11 deaths).

## 1.2 Governance and financial arrangements

In Poland, by law and by tradition, families are primarily responsible for care provision, with social institutions' intervening when families are incapable of undertaking adequate care measures[798]. In fact, a substantial majority of care is provided by families. About 5 % of the adult population is engaged in care provision either within their own household or outside. Out of these, more than every third person (34.1 %) provides intensive (more than 20 hours per week) care or assistance. Care providers are typically women in their 50s and people at risk of unemployment[799].

Public LTC benefits are rooted in separate legal regulations in the health and social sector, with different sources of financing and management structures.

In the health sector, provisions are made under the Act on health care benefits of 2004, financed from public sources (*Ustawa o świadczeniach opieki zdrowotnej finansowanej ze środków publicznych*)[800] and the Act on medical activity of 2011 (*Ustawa o działalności leczniczej*)[801]. Nursing and care units can be private, non-governmental or public, operating on the basis of a contract for service provision with the National Health Fund (*Narodowy Fundusz Zdrowia* – NFZ). In residential care, there is co-funding for any accommodation and catering required. A monthly out-of-pocket payment is set at 250 % of the minimum pension but cannot exceed 70 % of a resident's monthly income. All healthcare services are financed from the National Health Insurance.

Social sector services are granted according to the Act on social assistance of 2004 (*Ustawa o pomocy społecznej*)[802]. Care services are managed locally by local districts named *powiat* (most is residential care) or *gmina*[803] (some residential care and home care). Services are financed partially from the local government's budgets and partially out-of-pocket. The level of co-funding is set by local authorities, with possible partial or full exemption depending on the financial standing of the recipient.

Semi-residential services are provided by local authorities and funded from their financial resources (local taxes) and/or from the 'Senior+' programme targeted at creating and supporting day care activity homes and clubs.

Residential care is provided under the Act on social assistance as well as the Regulation of the Minister of Labour and Social Policy on social assistance homes of 2012 (*Rozporządzenie Ministra Pracy i Polityki Społecznej w sprawie domów pomocy społecznej*)[804] and the Regulation of the Minister of Labour and Social Policy on family care homes (*Rozporządzenie Ministra Pracy i Polityki Społecznej w sprawie rodzinnych domów*

[798] Sowa-Kofta A., *ESPN Thematic Report on Challenges in long-term care – Poland*, European Social Policy Network (ESPN), European Commission, Brussels, 2018. https://ec.europa.eu/social/main.jsp?pager.offset=20 and catId=792 and langId=en and moreDocuments=yes
[799] Jurek Ł., ' *Łączenie pracy zawodowej z opieką nad osobą starszą w Polsce'*, Uniwersytet Ekonomiczny we Wrocławiu, Wrocław. (2016)
[800] Dz.U. 2008 No 164, 1027 with further amendments.
[801] Dz.U. 2011 No 112, 654.
[802] Dz.U. 2019, 1507, 1622, 1690, 1818.
[803] Principle local level of administration in Poland.
[804] Dz.U. 2018, 734 with further amendments

*pomocy*)[805]. Residential services are financed by care recipients or their families up to the level of 70 % of individual incomes, however, for those incapable of covering the cost, co-funding by the local government is possible. According to data from the Ministry of Family and Social Policy, local governments at least partially cover the cost for 60 % of residential care recipients[806].

Cash benefits are provided by social security or funded the general taxation within family policy. There are several types of benefits granted based on different entitlements and eligibility criteria (see Section 1.3).

Nursing supplement (*dodatek pielęgnacyjny*) is a social insurance benefit and is granted based on the Act on old-age and disability pensions from the Social Insurance Fund of 1997 (*Ustawa o emeryturach i rentach z Funduszu Ubezpieczeń Społecznych*)[807].

Nursing allowance (*zasiłek pielęgnacyjny*) and special care allowance (*specjalny zasiłek opiekuńczy*) for people with disabilities or their carers are financed from the general taxes and provided in line with the Act on family benefits of 2003 (*Ustawa o świadczeniach rodzinnych*)[808]. Allowances for the carer (*zasiłek dla opiekuna*) are provided based on the Act on establishing and payment of carers' allowance of 2014 (*Ustawa o ustaleniu i wypłacie zasiłków dla opiekunów*)[809].

In October 2019, a benefit for adults incapable of living independently was introduced by the Act on a supplementary benefit for people incapable of living independently (*Ustawa o świadczeniu uzupełniającym dla osób niezdolnych do samodzielnej egzystencji*)[810]. The benefit is financed from the Solidarity Support Fund for People with Disabilities (*Solidarnościowy Fundusz Wsparcia Osób Niepełnosprawnych*), established in 2019[811].

Additionally, in the last few years, the government has launched several programmes supporting local authorities in providing care to dependent people, particularly by the social sector institutions (see Section 3). These programmes are based on annual grants to local authorities and aim at increasing access to care for different groups: older people, people with disabilities or family carers. Programmes are nationwide, but managed and supervised by voivodships[812] and typically require local co-funding of 20 % of the total costs.

Overall, public LTC expenditures are estimated as 0.8 % of GDP in 2019. In 2019, home care expenditure constituted 11 % and residential care 15 % of the total LTC public spending[813].

[805] Dz.U. 2012, 719.
[806] MRPiPS, *MPiPS-03 summary statistics from the social assistance offices*, 2019a.
[807] Dz.U. z 2017, 1383 with further amendments.
[808] Dz.U. 2020, 111.
[809] Dz.U. 2017, 2092 with further amendments.
[810] Dz.U. 1622.
[811] The fund was separated in 2019 with two sources: the Labour Fund (*Fundusz Pracy*) paid by employers and individual taxes in case of incomes exceeding PLN 1 million.
[812] Regional authority (*województwo*).
[813] Section 5 'Background statistics'.

## 1.3 Social protection provisions

### Healthcare sector services

Services are granted to all insured in need of medical treatment and rehabilitation due to a deterioration of their health status. Nursing homecare services are provided by LTC nurses or community nurses based on the decision of a primary care physicians. In chronic care homes (*zakłady opiekuńczo-lecznicze) and nursing homes (zakłady pielęgnacyjno-opiekuńcze*) care is provided to individuals based on a medical and functional assessment[814]. In hospitals, particularly in geriatric wards, functional abilities are assessed by the Complex Geriatric Assessment (*Całościowa Ocena Geriatryczna – COG*), however, this practice is not common in primary or nursing care as it is perceived as too complex and time consuming.

### *Social sector services*

Homecare services (*usługi opiekuńcze w miejscu zamieszkania*), including specialised homecare services (*specjalistyczne usługi opiekuńcze*), are provided to individuals requiring care and assistance at home or assistance with daily personal activities due to age or disability. Services are granted based on the assessment by a social worker, who evaluates the situation of the person in need in a family background interview and visit, if needed. The assessment includes an evaluation of the individual's needs[815], their household situation and income, as people with an income below the social assistance threshold may receive services free of charge. An administrative decision to grant services is issued following a family background interview, which is conducted with a specific questionnaire, that takes into account the medical condition of the prospective recipient, including a medical report. A regulation determines the template interview form and the way family background interview are conducted. The Act on the provision of social services by centres for social services[816] (*Ustawa o realizowaniu usług społecznych przez centrum usług społecznych*), introduced in July 2019, may change the provider, as local governments could decide to reorganise management and provision of services from social assistance to social services institution.

Residential care services in social assistance homes (*domy pomocy społecznej*) are granted based on care needs[817] and when the family is incapable of providing full-time assistance. The assessment of needs again is performed by the social worker from the local social assistance centre (*ośrodek pomocy społecznej*). Family care homes (*rodzinne domy pomocy*) provide full-time care to older people or people with disabilities based on the decision of the social assistance centre manager. Again, decisions are based on the family background interview and a medical certificate confirming that there are no contraindications to place a person in a family care home. Whilst social assistance homes are typically large, on average providing care to about 100 residents per institution, family care homes are small providing services to about eight residents per facility.

[814] Nursing residential care is provided for patients who with 40 or less points on the Barthel scale. If patients' health status improves, they are placed back at home.
[815] There are no unified standards in assessment of LTC home care needs in the social sector. The procedure and criteria are established by local authorities.
[816] Dz.U. 2019, 1818.
[817] There are no unified standards in assessment of LTC residential care needs in the social sector. The procedure and criteria are established by local authorities.

***Cash benefits***

The eligibility criteria for cash benefits are tailored for different types of beneficiaries depending on age, the level of need, individual or family income and social insurance status. Benefits provided to the person cared for include:

- The nursing supplement granted to all individuals aged 75+ eligible for the retirement pension from the Social Insurance Institution (*Zakład Ubezpieczeń Społecznych* – ZUS) or Agricultural Social Insurance Fund (*Kasa Rolniczego Ubezpieczenia Społecznego* – KRUS);
- The nursing allowance granted to individuals aged 75+ who are not entitled to nursing supplement due to insufficient social insurance history and lack of coverage or to children with disabilities or adults with severe or moderate disabilities since the age of 16 assessed by the Committee for Disability Assessment (*Zespół do spraw Orzekania o Niepełnosprawności*). Committees consist of medical doctors and other professionals and operate by district government (*powiat*);
- Benefit for adults incapable of living independently granted to individuals whose dependency has been assessed by the Social Security Institution[818]. Eligibility criteria include an income test as the benefit can be granted to individuals with monthly incomes from public sources (benefits, retirement of social pension, etc.) below PLN 1700/c.a. EUR 405.

Benefits provided to the carers include:

- Special care allowance provided to spouses or other family carers if they need to leave employment or cannot undertake employment due to caring for people with severe disabilities or incapable of living independently or caring for people who require intensive care due to medical treatment, rehabilitation or education. The allowance is granted upon a family income test (if monthly income per capita is below a threshold of PLN764/about EUR 182);
- Allowance for the carer that was introduced following the decision of the Constitutional Tribunal in 2013 on the unequal treatment of carers after support for carers of children with disabilities was introduced. The allowance is granted to carers of adults with disabilities who lost a right to receive support in 2013 due to the introduction of the above changes in legal regulations and provisions.

In principle benefits are care-related, however, there is no monitoring on whether resources have been used for this purpose. It might be assumed that in many cases their main function is to support the family budget, particularly in the case of benefits with age as the main eligibility criterion.

[818] For the purpose of this particular benefit a separate assessment of capability to independent living by the Social Security Institution was introduced, although full disability and work capability assessed by the Social Security Institution is also taken into account while granting a benefit.

## 1.4 Supply of services

Care services, either home or residential, can be provided by public (primary care and LTC facilities, social assistance offices, centres for social services), private and non-profit (including church organisations, such as *Caritas*) providers operating based on contracts with public payer institutions (e.g. National Health Fund). Older people and people with disabilities are the most important groups of recipients of care services.

In 2019, 37.2 % of the population aged over 65 received LTC cash benefits.[819]

According to Social Insurance Institution data, over 750,000 people applied for the benefit, out of whom 26 % were aged 60-74 and 44 % were above the age of 75[820]. In total, over 600,000 benefits were granted by different social insurance agencies (Social Insurance Institution, Agricultural Social Insurance Fund, the Ministry of the Interior and Administration, the Ministry of National Defence).

In the LTC healthcare sector, 431,000 patients (including 376,000 people aged 65+) are covered by residential care (provided by chronic care homes and nursing homes) while over 687,000 patients (including 572,000 aged 65+) get home-based LTC services. That means about 38.5 % of public LTC services in the healthcare sector are residential services and about 61.5 % are home care services (only taking into account patients aged 65+, the proportion of these services are similar).[821]

Still, the supply of services is very low, with only 11.8 beds in residential care per 1000 population aged 65+ in 2018[822] (OECD average: 47.2 per 1000 population)[823].

Next to it, there is a market of private providers, operating on a commercial basis, which concerns the social sector in particular. Private residential facilities have to be registered with a regional administration (voivode – *wojewoda*), but the monitoring of their actual activities is weaker than in public facilities.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

Different types of care services can be granted in case of medical and nursing needs or when family is incapable of providing care adequately to meet those needs. Although provision of care services is a mandatory task of social assistance and the number of recipients is growing, 20 % of local authorities had not provided this type of service in 2016. Older people and

[819] Section 5 'Background statistics'.
[820] ZUS, 'Informacja na temat realizacji świadczenia uzupełniającego', Warsaw, (2020)
[821] based on data of National Health Found for 2018.
[822] OECD Health data, *Long-term Care Resources and Utilization, Beds in residential long-term care facilities,* https://stats.oecd.org/Index.aspx?QueryId=30142 (downloaded April 10 2020)
[823] In accordance with the assumptions of the currently conducted works on the of deinstitutionalisation strategy, in the long-term perspective the share of residential LTC services in relation to total care services is expected to decrease, while, at the same time, the share of home-based LTC services in total LTC services is expected to increase.

carers are poorly informed on the specific support options. A survey study shows that over 70 % of informal carers have no knowledge about the availability of care options[824].

Survey data show that 6.5 % of households do not use homecare services because they are not available in the local community[825]. Programmes such as *Care 75+* have been implemented to increase access to homecare, particularly in communities where homecare was absent. Still, in the first year of the programme, its impact was moderate with over 300 local communities (out of more than 900 that were eligible) participating, but only 18 launching services for the first time.

In 2019, 3.4 % of the population older than 65 received care at home, while 2.7 % received care in an institution.[826] The number recipients has been slowly increasing over the past decade, i.e. in the social sector the overall number of care services' recipients grew by 34 % between 2010 and 2019 (MRPiPS, 2019a) and the number of social assistance homes inhabitants by 3 %.[827]

Homecare services in the social sector require co-funding, with exceptions applicable only upon approval by the local authorities. A survey study in the pomorskie voivodship shows that the monthly cost of care services from public institutions is similar to the cost of privately obtained care, which creates disincentives to use public services due to their cost, lower volume and lower flexibility of carers' work when compared to privately obtained services, particularly in the grey zone of the economy (i.e. by non-registered carers, including migrants)[828]. At the same time 51.7 % of households needing professional homecare do not use professional homecare services for financial reasons (2016 data).

The number of beds in publicly financed residential care facilities has not increased substantially[829/830], thus long waiting times for residential care on the one hand, and development of private residential care on the other hand, is observed. In principle, in the healthcare sector residents should stay for four to five months, but this period is in some cases extended or patients are moved to other types of residential care facilities, either in the social sector or to private facilities, which however typically, do not offer medical and rehabilitation measures to the same extent as nursing and care facilities in the health sector[831]. Territorial inequalities in access to residential care are observed, as services are more common in urban areas than in rural ones. Also publicly provided services, especially in the healthcare sector, are half as expensive as private ones. Market segmentation is observed, with public services accessible in rural areas, either in health or social sector as in many communities there is only one institution per district (*powiat*), and private ones most commonly developed in large, urban areas.

[824] Czerw A., Partyka O., Pajewska M., *Adekwatność i efektywność udzielanych świadczeń opieki zdrowotnej w odniesieniu do rozpoznanych potrzeb zdrowotnych osób starszych*, Raport końcowy NIZP-PZH, Warszawa, 2020.
[825] EU-SILC data 2016 (ilc_ats 15).
[826] Section 5 'Background statistics'.
[827] MPRiPS, *MRPiPS-05 summary statistics from social welfare homes*, 2019b.
[828] World Bank (2017), *Ocena stanu zdrowia i potrzeb opiekuńczych*, survey in pomorskie voivoship.
[829] MRPiPS, 2019b.
[830] CSiOZ, *Biuletyn Informacyjny Ministerstwa Zdrowia*, Warsaw, 2019.
[831] LTC facilities within public healthcare sector are provided in chronic care homes and nursing homes.

## 2.2 Quality

There is no formal quality framework regarding LTC services in particular, though various regulations address the presence of goal and process-oriented measures with respect to quality assurance separately in the healthcare and social sector.

In the healthcare sector, quality measures regarding LTC services are identical as in other types of services. Hospitals can voluntarily undergo an accreditation procedure provided by the Centre for Monitoring Quality in Healthcare (*Centrum Monitorowania Jakości w Ochronie Zdrowia)*. Provision of services is strictly regulated by the specific regulations of Minister of Health based on the Act on health care benefits financed from public sources as well as provisions of contract with the National Health Fund and covers procedures for medical treatment, nursing and rehabilitation as well as pharmaceuticals approved by the Agency for Medical Technology and Tariffication Assessment (*Agencja Oceny Technologii Medycznych i Taryfikacji – AOTMiT*). Regulations provide standards for care provision regarding facilities, equipment, registries etc. in different types of facilities, including nursing and care facilities, palliative care facilities and hospices. Monitoring of care quality remains the responsibility of local authorities, voivodship and eventually, the Ministry of Health.

In the social sector, standards are set particularly in respect to residential care, covering minimum standards of the room size, access to toilets and kitchen, sanitation requirements, rooms furnishings and equipment, food as well as minimal staff requirements. Residential care facilities often undergo voluntary ISO certification or obtain certificates regarding their performance, for example, being an abuse-free or respecting patients' rights institution. Community day care services are standardised within dedicated programmes, such as 'Senior+'[832] where minimum requirements regarding facilities and staff are set. Standards in home care are set covering broadly the types of services available (rehabilitation, nursing, education to social integration) and staff qualifications[833]. However, there are no standards of provision of specific services, including telecare which is gaining in popularity. In large cities, where the number of recipients is higher, care standards are often set by municipalities and social assistance centres[834]. Inspections by local authorities or the the Ministry of Family and Social Policy (particularly within dedicated programmes) might be carried out concluding with recommendations for improvement.

The number of private care institutions in the social sector is growing. Facilities need to be registered with regional authorities, however there are no specific requirements regarding their activities (staff, sanitation, equipment). The private sector remains highly unregulated and monitoring is questionable. To prevent abuse practices, in 2019, regional authorities (*voivode - wojewoda*) were given a right to monitor private institutions in the region and ban activities of unregistered residential care units.

[832] Within the programme established in 2015 and primarily entitle *Senior-Wigor* day care centres and clubs are supported with public funds for establishing a facility, renovation and partial coverage of costs related to running a day care centre or a club.
[833] Dz.U. 2005 No 189, 1598 Regulation of The Minister of Social Policy on specialist care services.
[834] Mejsner B., *Lokalne inicjatywy na rzecz ustalania kryteriów jakości i standaryzacji usług opiekuńczych świadczonych w miejscu zamieszkania. Przykłady dobrych praktyk, Tworzenie i rozwijanie standardów usług pomocy i integracji społecznej CRZL, WRZOS*, Warsaw, 2011. http://www.wrzos.org.pl/projekt1.18/download/Ekspertyza %20ZE %20OS.pdf

There is no mechanism for monitoring the quality of informal care, though in a case of a human rights violation or radically inadequate social conditions, police or social assistance might intervene.

## 2.3 Employment (workforce and informal carers)

The number of LTC workers per 100 people aged 65+[835] was estimated at 0.5 in 2016, almost the lowest in the EU-27 and the lowest on average in the OECD countries[836]. Employment in care services is low despite the fact that over the past decade, efforts have been made to increase the number of professionals in the workforce, especially in the healthcare sector, bringing to life new care professions, including LTC nurses and medical carers, and increasing the number of geriatricians. The total number of workers (both medical and non-medical) in residential LTC increased by 21 % between 2014 and 2018 (from 21,400 to 25,900 employees respectively)[837]. The number of medical doctors increased by 21 %, nurses by 15 % and medical carers by 59 % (CSiOZ, 2019). At the same time the number of professionals in rehabilitation also increased – medical doctors with the specialization in rehabilitation by 18 % and physiotherapist by over 30 %[838].

In social assistance homes the number of employees increased by 4 % between 2014 and 2018 (from 55,600 to 58,000 respectively) (MRPiPS, 2019b). The composition of staff strongly differs between the two sectors. In residential social care, the employment of medical staff is much lower, often below the level of need, equalling one medical doctor employed per 3400 inhabitants and one nurse per 15 inhabitants (MRPiPS, 2019b). The low number of physicians employed in the residential care in the social sector stems from the fact that residential social homes do not contract directly with the National Health Fund and use primary care services available in a given community. However, according to the Act on health care benefits financed from public sources, all patients have equal rights to access public healthcare benefits, including people in residential social homes[839]. Care facilities in the social sector are formally dedicated to people who do not require chronic nursing or medical care provided in the health sector. The general regulations on social protection state that in case of a need for medical LTC services, a resident of residential social home can be moved to chronic care home or nursing home.

Although an increase in the number of medical staff employed in LTC facilities is observed, the demand for services will grow substantially in the next few years whilst the population of physicians and nurses is ageing with every fourth medical doctor entitled to practice and every fourth nurse being above the age of 65 (CSiOZ, 2019). Projections from the National

[835] This indicator applies to all population aged 65+, regardless the need LTC or not.
[836] OECD, 'Who Cares? Attracting and Retaining Care Workers for Older People', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en.
[837] CSiOZ, https://cez.gov.pl/fileadmin/user_upload/Biuletyny_informacyjny/biuletyn_statystyczny_2019_5db016ddd0b8d.pdf, 2019.
[838] MZ.
[839] Primarily health care doctors and nurses have higher capitation rate for providing healthcare benefits to residents of such facilities

Chamber of Nurses and Midwives show that because of workforce ageing there will be an undersupply of more than 68,000 nurses by 2030[840].

Inequalities in wages between the healthcare and social sector exist[841]. Work in the social sector is typically related to poorer wages and poorer prestige. Wage differences are anchored in regulations on minimum wages in professions in health and social sector, with minimum wages for physicians and nurses twice as high in the health sector as in the social sector[842].

There is a large workforce of informal carers. Although frequently providing care-intensive work, they lack support in their everyday performance in the form of respite care, trainings and psychological help. This type of assistance has been largely absent, provided occasionally by non-governmental organisations with the support of local authorities[843]. A programme to stimulate the development of respite care was only launched in 2019.

Informal carers might face difficulties in combining work and care, as cash benefits are provided if they have to give up employment due to their care responsibilities or in families with low per capita incomes. A survey by the National Institute of Public Health – National Institute of Hygiene (Czerw et al., 2020) shows that 65 % of cases where informal carers have left work has led to a significant loss of income by the household. Carers of older people to a large extent remain unaware of the types of support they may be entitled to. While the majority of households tend to decide to take care of the older relative in need of care, high-income households tend to employ non-registered, non-professional carers or live-in migrants, particularly from Ukraine. In 2014, there were 14,000 migrants registered in domestic work, though most of migrants are unregistered[844]. The supply of migrant care may have been impacted recently by the pandemic as many foreign workers left the country.

## 2.4 Financial sustainability

It is estimated that the total public expenditure on LTC in Poland amounted to 0.8 % of GDP in 2019 (See Section 5 'Background statistics'). Cash benefits constituted 74 % of the total LTC expenditures, residential care 15 % and homecare 11 %. According to the 2021 Ageing Report projections' reference scenario, assuming no changes in the structure of benefits' provision and similar cost profiles, the total LTC expenditure is foreseen to grow to 1.1 % of GDP in 2030 and 1.7 % of GDP in 2050. If an assumption is made that the structure of benefits provision and their costs will change, converging to an EU-27 average (the risk scenario), the expenditure in 2050 is foreseen to grow to 3.1 % of GDP. Although the increase is higher, due to an increase in the use of services, projected costs in relation to GDP in

[840] NIPiP, *Raport Naczelnej Rady Pielęgniarek i Położnych. Zabezpieczenie mieszkańców domów pomocy społecznej w świadczenia pielęgniarskie – raport z badania ankietowego*, Warsaw, 2018.
[841] Inequalities in wages are connected to level of qualification required in both sectors:
health care sector needs professionals with higher qualification (most common higher degree) and demanding higher responsibility thus their wages are also higher than social care workers;
social care workers in social sector do not need be as qualified (often they are workers with secondary education and some kind of additional care training) and thus their wages are lower than medical care and nursing staff in the healthcare sector.
[842] Regulation of the Council of Ministers of May 15, 2018 on the remuneration of local government employees; Law of June 8, 2017 on the method of determining the lowest basic salary of certain employees employed in healthcare entities.
[843] Le Bihan C., Lamura G., Marczak J., Fernandez J-L., Johansson L., Sowa-Kofta A., *Policy measures adopted to support long-term care*, *Eurohealth*, WHO, 2019.
[844] The data includes all types of migrant workers, not only those who work for private households as unprofessional carers.

Poland are well below the EU-27 average (1.9 % in 2030 and 2.5 % in 2050 in the reference and 2.1 % in 2030 and 3.4 % in 2050 in the risk scenarios). Both scenarios assume that half of the life expectancy gains will be spent in good health and with no care-demanding disabilities.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Strengthening policies towards the work-life balance of carers of people with disabilities and older people is needed by rethinking eligibility criteria, which might demotivate them from taking up employment. Supporting employers in implementing care-friendly solutions (flexible working, telework, care leave), although challenging, could be one of options for increasing work-life balance.

There is a public discussion on the availability of psychiatric care for various groups, including children and older people. Mental health services are provided inpatient, mostly in hospital care[845], and outpatient in mental health clinics and psychical health centres. The number of specialists per head of population is 9.2 psychiatrist per 100 thousand people in 2017[846]. In the case of older people, strengthening Alzheimer and dementia care is a challenge, which is one of the main interests of public bodies which are developing healthcare for the older population.

# 3 REFORM OBJECTIVES AND TRENDS

The European Commission Country Report 2020 (European Commission, 2020) and Country-specific Recommendations[847] indicate that Poland lacks a comprehensive, strategic approach to ensuring publicly based, high quality LTC. Although there are no major reforms currently planned to increase coherency of LTC sector, various efforts have been made over the past few years to strengthen provision of LTC services.

In 2018 a strategic document called 'Social Policy Towards Older People 2030. Security – Participation – Solidarity' (*Polityka społeczna wobec osób starszych 2030. Bezpieczeństwo – Uczestnictwo – Solidarność*)[848] was adopted with an aim of creating an ageing-friendly social environment, stimulating the activity of older people, health education, increasing access to care for people with functional impairments and investing in nursing and care professions. In line with the policy, the Ministry of Family, Labour Social Policy launched several programmes extending up-to-date provisions and continues activities undertaken in previous years, such as the 'Senior+' programme supporting community day care for people aged 60+, which has been operating since 2015.

Since 2018, a programme 'Care 75+' (*Opieka 75+*) has been in place, supporting financially the provision of care services in rural areas and towns with up to 60,000 inhabitants, which are particularly prone to population ageing due to migration. Local authorities might be

[845] These type of services are also provided outpatient by mental health clinics and Psychical Health Centres (according to implementing currently scheme of psychiatric care system).
[846] Eurostat [hlth_rs_spec].
[847] http://data.consilium.europa.eu/doc/document/ST-10174-2019-INIT/en/pdf.
[848] MRPiPS, *Polityka społeczna wobec osób starszych 2030. Bezpieczeństwo – Uczestnictwo – Solidarność*, Warsaw, 2018. https://www.gov.pl/web/rodzina/polityka-spoleczna-wobec-osob-starszych-2030-bezpieczenstwo-uczestnictwo-solidarnosc

granted a subsidy to provide services by full-time professional carers. The programme was not widely recognised and met with cautious reception among local policy makers. About 900 *gminas* were eligible to participate in the programme, but eventually only one third participated in its first year. The same year, a complementary programme 'Care services for people with disabilities' (*Usługi opiekuńcze dla osób niepełnosprawnych*), targeting people with disabilities under the age of 75 was introduced.

Informal carers are provided with governmental support within a programme entitled 'Respite care' (*Opieka wytchnieniowa*) that started in 2019. Local authorities can apply for financial resources to improve access to respite care services, which previously have almost been absent. Besides respite care, health education and training for carers of children with disabilities or adults with disabilities, including older people, are foreseen. The above listed programmes are financed from the Solidarity Support Fund for People with Disabilities (*Solidarnościowy Fundusz Wsparcia Osób Niepełnosprawnych*).

Local governments are also supported in organising meals on wheels for older people or targeted social assistance benefits for acquiring meals under a programme 'Meal at school and at home for the period of 2019–2023' (*Posiłek w domu i w szkole na lata 2019–2023*).

Cash benefits for adults incapable of living independently were introduced late in 2019. A definition of incapability to live independently with a new assessment for this purpose was implemented. The benefit of PLN 500 (around EUR 119) is targeted at individuals with lower incomes, as a support measure in need for LTC.

The government, together with non-governmental organisations and experts, is working on a strategy of supporting independent living with social services. The strategy is expected to be announced in summer 2020.

In the healthcare sector, efforts have been made to improve the quality of treatment for older people and particularly to improve the coordination of care. For this purpose, professional teams will be established in primary care, consisting of a physician and a nurse, who will personalise the care path for each patient, from prevention via treatment to rehabilitation if necessary. Each patient will be supported by administrative staff who will guide the patient though the medical process. The teams should begin to operate in October 2020, but it remains unknown whether the COVID-19 pandemic will impact (and potentially postpone) the reform.

In spring 2020, the COVID-19 pandemic has had an impact on LTC performance, particularly in residential care. Overall about 7 % of the total infections were reported in LTC social assistance homes in the social sector and 3 % in residential facilities in the healthcare sector[849]. According to the Ministry of Family, Labour and Social Policy less than 0.5 % of the total number of residents in LTC social sector institutions got infected[850]. However, residential care institutions were largely unprepared for the epidemiological threat. The main risk factors included insufficient sanitary procedures related to the isolation of those

[849] Rządowe Centrum Bezpieczeństwa, *Raport 'COVID-19 Sytuacja epidemiologiczna w Polsce i na świecie'* – stan na 4 czerwca 2020 godz. 14.
[850] https://www.gov.pl/web/rodzina/domy-pomocy-spolecznej-dobrze-zabezpieczone

potentially infected, shortages in equipment (masks, gloves) particularly in the social sector and staff shortages, with medical and nursing staff working in several institutions (LTC, hospital, primary care unit). Also access to COVID-19 tests was poor. Some local authorities faced difficulties in response to infections, others immediately introduced measures aimed at isolation, protection of workers and patients. The national consultant in infectious diseases published recommendations for residential facilities regarding staff employment in one unit only, use of protection equipment, prohibition of visitations and quarantine procedures[851]. More recommendations have been issued[852]. In chronic care homes and nursing homes in LTC in the healthcare sector, obligatory COVID-19 tests for patients/residents before admission to the facility were introduced. Only patients/residents with negative test results can be admitted to the facility. The COVID-19 tests for these group of patients are controlled by the National Health Found.

In community centres (centres for people with special needs (*środowiskowe domy samopomocy*) and some day-care centres in social sector have been temporarily closed. Restrictions were imposed on admission to social assistance homes in order to safely admit new residents.

The COVID-19 epidemic has highlighted and exacerbated the current problems of in all major aspects as well as created the basis for accelerating certain reforms in the sector and changing the approach for future reforms in this field.

Poland took public action to counteract the effects of the epidemic. These actions included aspects of access, quality, workforce and informal carers and stepping up additional financial support to LTC systems.

The Ministry of Family and Social Policy decided to put an additional PLN 50 million towards addressing needs related to protection in social welfare homes. Additionally, resources from the European Social Fund will be used for promoting independent living and the COVID-19 response.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

LTC sector in Poland is still small in terms of the number of recipients in relation to the older population in need of LTC and public expenditure on benefits and services. In the face of the ageing process, the sector needs to be broaden and this is being slowly addressed by the policies and programmes implemented over the past few years, which concentrate less on

[851] http://www.dps.pl/koronawirus/inne/zalecenia-krajowego-konsultanta-w-dziedzinie-chorob-zakaznych-z-dnia-10042020-dla-dps-ow-i-jednostek-opiekunczo-leczniczych-22

[852] In mid- March 2020 Ministry of Health prepared, upon request of Ministry of Family, Labour and Social Policy, general recommendations for residential facilities in social sector (such as social assistance homes).
Also, at the very beginning of April 2020, Ministry of Health published online general recommendations for and palliative home care as well as LTC in healthcare sector (both residential and home care), the latter have been updated at the beginning of May 2020. Both recommendations were developed by group of experts (incl. national consultants) and consulted with Main Sanitary Inspectorate (Główny Inspektorat Sanitarny – GIS).
Recommendations for specific scopes and types of healthcare benefits as well as for individual groups of medical professionals and healthcare facility managers are published online and updated on an ongoing basis by Ministry of Health. Also other public entities published recommendations in their area of operation.

activation measures and more on care. Among the challenges that still need to be addressed are:

- introduction of mechanisms that will widen access to community-based care for older people enabling more independent living and assure the sustainability of measures introduced under specific programmes (such as 'Care 75+', 'Respite Care', 'Senior+');
- improvement of the coordination of care between the two sectors, particularly in the transition from hospital to care facility or home;
- assurance of coherency and transparency with respect to care needs assessment, available cash benefits and care options for people with disabilities and dependency;
- recognition of informal carers in LTC policy, providing them with support to balance work and care as well strengthening their performance by respite options, psychological support and training;
- investment in care and nursing professions in LTC through an increase in wages and a decrease of wages' inequality between the health and social sector in similar professions, improvement of working conditions and increasing the prestige of care work;
- closer monitoring and quality management in LTC institutions, particularly in the private sector.

# 5 BACKGROUND STATISTICS

| *5.1. Demographics* | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 38.1 | 38.0 | 37.0 | 34.1 |
| Old-age dependency ratio, 2019 | | 18.9 | 26.4 | 35.6 | 52.2 |
| Population 65+ (in millions), 2019 | Total | 5.1 | 6.7 | 8.4 | 10.3 |
| | Women | 3.2 | 4.0 | 5.0 | 5.8 |
| | Men | 1.9 | 2.7 | 3.4 | 4.5 |
| Share of 65+ in population (%), 2019 | | 13.5 | 17.7 | 22.7 | 30.1 |
| Share of 75+ in population (%), 2019 | | 6.0 | 7.2 | 10.8 | 15.2 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 17.6* | 18.5 | | |
| | Women | 19.5* | 20.4 | 21.8 | 24.2 |
| | Men | 15.1* | 16.1 | 17.6 | 20.2 |
| Healthy life years at the age of 65, 2018 | Total | 7.2* | 8.5 | | |
| | Women | 7.5* | 8.8 | | |
| | Men | 6.7* | 8.2 | | |

**data for 2010*

| *5.2. People in need of LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 2,556.3 | 2,825.3 | 3,117.9 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 1,374.1 | 1,745.4 | 2,220.8 |
| | Women | | 871.9 | 1,081.7 | 1,331.1 |
| | Men | | 502.2 | 663.7 | 889.7 |
| Share of potential dependants in total population (%), 2019 | | | 6.7 | 7.6 | 9.2 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 20.2 | 20.7 | 21.5 |
| Share of population 65+ in need of LTC** (%), 2019* | | 35.5 | 36.0 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| *5.3. Access to LTC* | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 2.7 | 2.8 | 3.2 |
| Share of population 65+ receiving care at home (%), 2019 | | | 3.4 | 3.5 | 4.1 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 37.2 | 43.9 | 45.6 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 30.0 | 30.2 | 33.6 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 184.2 | 211.8 | 212.2 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 57.5 | 46.7 | | |
| | Women | 58.6 | 47.1 | | |
| | Men | 54.5 | 45.7 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 7.4 | 7.6 | | |
| | Women | 8.5 | 8.8 | | |
| | Men | 5.8 | 5.8 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 51.7 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 6.5 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 184.9 | 195.3 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 0.6 | 0.5 | | |
| | % Women | | 97.0 | | |
| Share of population providing informal care (%), 2016 | Total | | 10.2 | | |
| | Women | | 11.7 | | |
| | Men | | 8.0 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 34.1 | | |
| | Women | | 36.9 | | |
| | Men | | 27.5 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.8 | 0.8 | 1.1 | 1.7 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.8 | 0.8 | 1.4 | 3.1 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 45.5 | 15.0 | 13.5 | 15.4 |
| Public spending on home care as % of total LTC public spending, 2019 | 10.5 | 11.0 | 9.7 | 10.6 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 44.0 | 74.0 | 76.8 | 74.0 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.4 | 0.4 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# PORTUGAL

***Highlights***

- *Adverse demographic trends clearly point to a potential increase of the population in need of long-term care (LTC) in Portugal and to an increase in public spending on LTC. This, in turn, raises issues regarding the system's financial sustainability.*
- *In the formal LTC system in place, beyond LTC Social,the National Network for Integrated Continuous Care (RNCCI) integrates health and social, and includes different types of services, most of which show very high usage rates. Issues regarding access and affordability persist.*
- *Portugal is one of the EU-27 Member States with the highest rates of care provided by informal caregivers. Overlooked until recently, the situation of informal carers will change following the recent approval of a formal status for them.*
- *Ensuring that the implementation of the status effectively supports informal carers is a major challenge to be addressed, along with promoting increased access to and affordability of formal LTC.*

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The LTC system in Portugal is expected to face increasing pressure in the coming years especially due to the ageing of the population that will probably translate into higher demand and into less financial resources deriving from taxes in order to ensure the future supply of LTC. Portugal ranks sixth among the countries with the most aged population in the world and the Portuguese population has been shrinking in recent years, especially in the interior of the country. From 10.3 million in 2019 it is expected to decrease to 10.1 million in 2030 and to 9.4 million in 2050. All regions registered decreases except for the region of 'Lisboa e Vale do Tejo'. This partially contrasts with the scenario for the EU-27[853] that is expected to see its population increase from 446.8 million in 2019 to 449.1 million in 2030 before decreasing to 441.2 million in 2050.[854]

The share of the population aged 65+, which already increased from 17.7 % in 2008 to 21.8 % in 2019, is expected to reach 26.2 % in 2030 and 33.7 % in 2050 (again, the process is more marked in the interior). Likewise, the share of the population aged 75+, which increased from

[853] EU-27 refers to the current 27 Member States of the European Union.
[854] All data used in the text come from Section 5 'Background statistics' unless explicitly stated otherwise.

8.1 % in 2008 to 10.5 % in 2019, is expected to further increase to 13.2 % in 2030 and 19.6 % in 2050. The Old-age dependency ratio, which stood at 26.6 in 2008 and at 33.9 in 2019 is expected to reach 43.1 in 2030 and 62.8 in 2050.

These figures are all significantly above the EU-27 average and clearly point to a potential increase in those in need of LTC in Portugal. And indeed, the share of potentially dependent people in the total population is estimated to increase from 8.1 % in 2019 to 9.0 % in 2030 and to 10.4 % in 2050. Additionally, it should be noted that, in 2019, 32.6 % of the population aged 65+ had at least one severe difficulty in personal care and/or household activities.

## 1.2 Governance and financial arrangements

In a context where informal care is still predominant, health and social policies in Portugal have tried to respond, in the last few decades, to the increasing care needs of an ageing and/or dependent population by developing a LTC system based on the provision of community-based and institutional services.

Since 2006, LTC has formed one of the branches of **the national network for integrated continuous care** (RNCCI). The RNCCI − created in 2006 and implemented after 2007 − provides rehabilitation services in the convalescent care medium- and long-term care and home care. There are also specific responses in terms of mental healthcare and pediatric care and palliative care of lower complexity. The network **was set up jointly by the Ministries of Health and of Labour, Solidarity and Social Security**.

LTC is provided in response to dependency associated with (among other things) the ageing process. It is aimed at providing humanised, qualified and comprehensive care at the point when it is needed, and reflecting the diversity of ways in which ageing is experienced, by the creation of proximity services throughout the territory. These principles are emphasised in the RNCCI **legislation**, as is the promotion of more equity in accessing care. The programme is aimed at responding to increasing social, health and demographic challenges: for example, the ageing of the Portuguese population; the heterogeneous nature of the social situation of older people; the prevalence of chronic debilitating illnesses; and the decreasing availability of 'traditional' family carers. Both the health and the social security systems are necessarily involved in responding to such challenges.

The provision of LTC is embodied in the organisational model of the RNCCI. This model – based on unified objectives and methods − introduced an important reform in the provision of LTC services by the national health system and the social security system, aimed at promoting high-quality practices. Thus, the axial strategies defined for the implementation of RNCCI result from **strong coordination between the different levels of health services, and between these and local/regional social services. Non-profit organisations and the private sector are also important partners in the programme**.

**Long-term care is tax-financed** by taxes raised at the national level. The RNCCI has a specific financing model based on the types of services provided, which may include funding from both the Ministry of Health and the Ministry for Solidarity, Employment and Social Security, as well as from users themselves through fees (only in the social financing component).

In 2019, **public spending on LTC in Portugal stood at 0.4 % of GDP**, which is significantly below the EU-27 average (1.7 %).

Over time**, Portugal has been identified as one of EU-27 Member States with the highest share of out-of-pocket funding for LTC** (e.g. ERS, 2015). In 2017, household out-of-pocket payment represented 0.5 % of GDP, 0.4 % regarding social function and 0.1 % regarding health function.

No social co-payment is required for convalescence units or for palliative care of lower complexity. The national health system (and other subsystems) ensures funding. Users should pay the costs related to social support. However, these costs may be co-paid by the social security system if the value of the movable assets of the user's household is lower than 240 times the social support index (IAS), i.e. EUR 105,314.4 in 2020.[855] The exact amount of the co-payment depends on the household's income. There is no legal obligation for family members to contribute towards the costs if the dependent person is unable to pay. The Civil Code establishes that parents and children both have a duty to assist. However, it does not mention caring. It rather states that the duty to assist includes the obligation to provide alimony and to contribute, while living together, to household expenses. Private specific LTC insurances do not play a role in Portugal. In 2018, a total of 2,671,371 people (i.e. around 26 % of the Portuguese population) were covered by a private health insurance.

## 1.3 Social protection provisions

The so-called dependency supplement is a **cash benefit for dependent people who are cared for**. It may be granted to a person requiring the permanent assistance of another person to perform the essential activities of daily living. It may be attributed to: i) recipients of an invalidity, old-age or survivor's pension under the general social security scheme or the voluntary insurance scheme; ii) recipients of an old-age and survivor's pension under the non-contributory scheme; iii) recipients of the social benefit for inclusion and to iv) people who are not pensioners yet with chronic illness which may cause disabilities or in a situation of dependency formally recognised by social security services. The amount of the benefit varies according to the level of dependency recognised by the social security services. In 2020, the monthly amount varied between EUR 105.90 and EUR 190.61,[856] respectively, for: a) people who are unable to perform tasks relating to feeding or to mobility autonomously or to looking after personal hygiene; and b) people who, in addition to meeting the above criteria for the first degree of dependency, are bedbound or have been diagnosed with severe dementia.

Following the approval of a formal status for informal carers in September 2019, a **cash benefit for informal carers** has been in place since April 2020 (see Section 3). Currently, a pilot-phase has been implemented in approximately 10 % of Portuguese municipalities for a period of 12 months. Also, from April 2020, a set of **in-kind benefits for informal carers** is in place, within the scope of the aforementioned approval of a formal status for informal carers (see Section 3). These add to other in-kind benefits (made available or supported by the

[855] In 2020 the amount of the social support index is set at EUR 438.81.
[856] These amounts relate to benefits granted under the general social security scheme. For other recipients, the respective amounts are EUR 95.31 and EUR 180.02.

social security system) for people cared for and their carers which were already in place before the approval of the status, which include for example day centres and centres offering occupational activities.

The system for the verification of permanent disabilities is responsible for the **initial evaluation and eventual follow-up** of cases. It consists of medical committees running within the Institute for Social Security (ISS, I.P.). In the case of hospital discharge, 'a social worker who is part of the care team conducts an evaluation of the home of the patient, and assesses the availability of an informal caregiver; at the same time, the hospital team (i.e. nurses, doctors, pharmacists, social workers and a nutritionist) assess the patient thoroughly before discharge, after which they take a dossier including team contacts – available 24h/7. On the day of discharge, the patient receives a visit from a nurse, and the following day, a home visit from the physician. Third, once set up at home: the follow up is managed by the primary care health centre which coordinates the care with the hospital'.[857]

## 1.4 Supply of services

**Related to RNCCI, it comprises both public and private units with agreements signed with the state.** By June 2019, the large majority of places were provided by private not-for-profit entities (75.3 %). The remainder were provided by private for-profit entities (22.4 %) and by public units (2.3 %) (ACSS, 2019). **The RNCCI provides four main types of health and social support care services** which should provide a continuum of formal care, taking place in: residential care services (convalescence, medium-term care, long-term and maintenance units[858]) and home care services (integrated continued care teams). Patients must be referred by a hospital or health centre (there are referral/discharge teams in all hospitals and in all ACES – group of health centers), after which an assessment is made by the local coordination teams of the RNCCI. The assessment is made according to a set of criteria that includes the degree of dependency and/or the presence of a serious illness or injury. In parallel, there are also private for-profit services providing LTC operating independently.

The assessment of the implementation of the 2016-2019 development plan for the RNCCI shows a positive quantitative evolution overall. However, some **imbalances regarding the provision of institutional versus home care services** are also identified. The latest monitoring report of the RNCCI, regarding the first half of 2019 (ACSS, 2019), registered an increase of 2.7 % in the number of beds available (residential care) compared with the end of 2018, to a total of 8627.[859] This increase compares with the reduced number of places available (-1.5 % between the end of 2018 and the end of the first half of 2019) within the home-based health care teams, providing support to dependent or convalescent people whose situation does not require residential care, to a total of 5643, due to readjustment of the number of places in relation to the available human resources.

[857] OECD, *Ensuring an Adequate Long-Term Care Workforce – Final report* March 2019, 2019a, p. 119.
[858] But not residential homes.
[859] The figures presented do not include services specifically allocated to paediatric care and for mental health. It should be noted that the RNCCI may be used by all age groups even if being aged 65 or more is a main overarching priority criterium for accessing social LTC (see next section).

Still according to the monitoring report of the RNCCI, the different types of care within institutional services showed high usage rates. Conversely, the usage rate for home-based care services stood at 73 %.[860]

The formal LTC **workforce** is deemed to be around 17,600.[861] The number of informal carers is estimated to be approximately 1.1 million.[862] Women are deemed to represent the majority of informal and, especially of, formal care workers, most of which have low levels of education (see Section 2.3).

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

**Problems of access to LTC remain in Portugal, with with some developments**. Eligibility criteria as far as RNCCI is concerned, are related to health and social needs, regardless of age, for example frailty and/or temporary or permanent dependency/disability, physical and /or mental and difficulty in ADL's. As regards social LTC, the criteria differs slightly according to the service. The main overarching priority criterion is age, i.e. being aged 65 or more. Dependency, for instance, is a priority criterion for access to home care services but detrimental for access to night centres.

In 2019, only 1.8 % of people aged 65+ received formal LTC care in Portugal – 1.2 % received care in an institution and 0.6 % received care at home. A recent OECD study compares the figure of 1.9 % with 10.8 % as the average in a set of 25 OECD countries and 0.9 % in Poland and 16.2 % in Sweden, respectively the EU-27 Member States represented in the study with the lowest and highest figures.[863]

The availability of services with regards to residential care is lower than demand. As mentioned above, most types of services within residential care have usage rates of over 90 % (some close to 100 %) and only the usage rate for home-based care services stands at a lower level which may be related with the increased availability of these services. In June 2019, waiting lists as a percentage of the total number of places available were the following: 4.1 %, in the case of integrated continued care teams, 23.5 % in the case of convalescence units, 16.9 % in the case of medium-term care units and 18.2 % in the case of long-term care units. Waiting lists were much longer in the regions of 'Lisboa e Vale do Tejo' and 'Alentejo' than in the remaining regions. Portugal is highlighted as a country where the increase in the proportion of LTC recipients who received care at home rose the most between 2007 and 2017, from 64 % to 68 % (OECD, 2019b). In any case, it should be noted that, in 2019, only 6.4 % of population aged 65+ used home care services for personal needs (in the past 12 months).

[860] ACSS, *Administração Central do Sistema de Saúde, I.P. (2019), Relatório de Monitorização da Rede Nacional de Cuidados Continuados Integrados (RNCCI) – 1º semestre,* 2019.
[861] Estimated on the basis of the number of LTC workers per 100 individuals aged 65+.
[862] Estimated on the basis of data provided by the Eurostat regarding the population aged 15+ (8,880,498) and the percentage of population aged 16+ providing informal home care services (12.3 %). For comparability reasons the year used was 2016.
[863] OECD, *Health at a Glance 2019: OECD Indicators*, OECD Publishing, Paris, 2019b.

The low number of people aged 65+ receiving formal LTC care may be linked to the shortage of LTC workers (see Section 2.3). As noted by a study commissioned by the International Labour Office (ILO), 'the absence of formal LTC workers results in the exclusion of large parts of the older population from quality services. (…) In Portugal more than 90 % of the population is excluded'.[864] In this same study, the number of formal workers in LTC (FTE) for a 100 people aged 65+, in Portugal in 2014, was 0.4. However, in recent data reported to the OECD Health Data 2020 – Questionnaire, the number of formal workers in RNCII was 0.56.

Also, **problems of affordability persist**. Some services are provided for free but, for the most part, out-of-pocket payments are requested, related to social financing, depending upon means-testing (see Section 1.2). As aforementioned, Portugal has been identified as one of the countries with the highest share of out-of-pocket funding for LTC and indeed this limits its affordability. In 2016, 30.8 % of households in need of LTC were not using professional home care services for financial reasons.

## 2.2 Quality

The **RNCCI quality framework** includes models of quality promotion and management, established by Dispatch of the Government's members responsible for the fields of health and social security. It should be mandatorily applied in every unit and team of the RNCCI – public and private, for profit and not-for-profit. Furthermore, all units and teams are subject to a periodic evaluation process that integrates both the annual process of self-evaluation and external evaluation.

Thus, the LTC quality framework is monitored, assessed and enforced in different ways. Minimum quality standards for both equipment and supporting teams were established for the units of the RNCCI. The standards cover structure, human resources and quality of care. Furthermore, the LTC quality framework also includes: a) the evaluation of users' complaints and suggestions; b) the analysis of surveys to users, family members, informal carers and professionals; c) internal audits; d) inspections of a sample of providers.

Units should have written internal proceedings disseminated to all professionals. A welcome guide for users and family members should be available. A biopsychosocial assessment should be made at the time of referral and included in the clinical process. Reassessments should be made whenever felt necessary.

A system of certification is in place within the scope of the cooperation programme for enhancing quality and safety of social answers. The process is voluntary and certification is granted by external independent entities duly certified by the Portuguese quality system through audits on the basis of criteria defined by the Institute of Social Security who is also responsible for regulation. Portugal also has in place accreditation procedures for providers of long-term care. The process is voluntary.

[864] Scheil-Adlung, X., 'Long-term care protection for older persons: a review of coverage deficits in 46 countries', *Extension of Social Security series*, No 50, ILO, Geneva, ILO, 2015, p. xii.

It should be noted that joint Dispatch 176-D/2019, of the Minister of Labour, Solidarity and Social Security and the Minister of Health created the National Commission for the Coordination of the RNCCI, which should 'propose criteria for certification, accreditation and assessment of the quality of the answers provided by the network, ensuring due articulation between the competent entities'.[865] Furthermore, the Commission should 'identify procedures, protocols and indicators allowing for the qualification of care provided and the emergence of good practice and promoting the evaluation of results in order to consider possible performance incentives to reward units and/or its professionals' (República Portuguesa, 2019, pp. 570-(06).

**Ensuring and monitoring the quality of informal care lacked, until very recently, specific framework.** This changed in September 2019 with the approval of a formal status for informal carers (see Section 3). According to this new status, the Institute for Social Security and the relevant departments in the field of health are responsible for monitoring, inspecting and assessing the fulfilment of the measures envisaged for their respective areas of intervention. Furthermore, they should provide the tools and the means necessary for its realisation. Ensuring a concrete definition of the quality framework for informal care and its enforcement along with the similar framework for formal care seems a crucial next step.

The status does not include any specific article regarding the way the informal carer's situation is assessed and monitored over time. In any case, the support measures the informal carer is entitled to give indications on how this may be realised (see Section 3).

## 2.3 Employment (workforce and informal carers)

**Portugal has a high deficit in LTC workers**. In Portugal, there are only 0.8 LTC workers per 100 people aged 65 and over, which compares with 3.8 on average across 25 Member States. In 2016, 95.8 % of formal LTC workers in Portugal were women, compared with 90.8 % in the EU-27.

On the positive side, the OECD notes that Portugal is one of the European countries where the growth rate of the LTC workforce is high (OECD, 2019a). This is in itself positive even if one should be aware that the sharp growth rate is partly due to the low starting base.

According to OECD data nearly two out of three (64 %) **LTC workers in Portugal have low levels of education**, which compares with a mean of 15 % in a set of 20 OECD countries. Perhaps even more striking is the fact that this figure is nearly double the second highest proportion of low-educated LTC workers, in Italy (35 %).[866]

Also national studies have revealed that healthcare assistants are usually poorly educated, poorly trained and poorly paid women.[867] They concluded that the main reasons for being a LTC healthcare assistant were financial need, the absence of other job offers and job stability

[865] República Portuguesa, *Despacho No 176-D/2019, do Ministro do Trabalho, Solidariedade e Segurança Social e da Ministra da Saúde, Diário da República*, 2.ª série, No 3, 4 January 2019, 2019a, p. 570-06.
[866] OECD, *Health at a Glance 2019: OECD Indicators*, OECD Publishing, Paris, 2019b.
[867] E.g. Pires, R., '*As representações sociais e as práticas do ajudante de lar: Projeto de intervenção "EnvelheSer com cuidados", Masters' thesis, Portalegre, Instituto Politécnico de Portalegre*', 2015.

(as demand for such jobs exceeds supply). In many cases, the job followed a period of unemployment.

Even if job opportunities in the field exist and probably provide relatively stable contracts, **remuneration is far from attractive**. Current wages in the LTC workforce are generally low and personal care workers have lower salaries compared to nurses. According to a recent report by the OECD, the average annual salary of a personal care worker is close to the minimum wage (EUR 635/month, in 2020) while a nurse in the beginning of her career is paid EUR 900/month. (OECD, 2019a).

Precise information on the remuneration of LTC workers is not readily available from national sources. However, it is possible to use the remuneration of workers providing human health and social support as a proxy. In April 2019, the basic monthly salary of those workers was EUR 837.10, compared with EUR 992.50 for all workers (i.e. 84 %).[868]

Additionally, it seems worth mentioning that, as noted by the OECD, wages in the LTC sector follow salary tables negotiated between the three main unions representing providers and the public Institute for Social Security. They take into account the workers' education and experience and they cover the non-profit sector (OECD, 2019a).

The report also notes that, in order to **facilitate recruitment and retention**, a set of countries including Portugal have tried to improve the image among young workers and students or provide incentives to (re)enter the sector for example, through initiatives such as 'Proud to Care' and 'Care Ambassadors'. Additionally, some local programmes, with the support of municipalities, have been established to promote a positive image of the LTC workforce (OECD, 2019a).

Perhaps fostered by the overall low education levels of LTC workers, recruitment of workers from abroad to work in LTC in Portugal is exempt from a labour market test if it belongs to the list of occupations where there are labour market shortages (OECD, 2019a).

Apart from care which is made available through the existing formal network, as briefly described above, it is important to mention the role of informal care within LTC provision in Portugal. Statistics identify **Portugal as one of the EU-27 Member States with the highest rates of care provided by informal caregivers**. In 2016, 12.3 % of the Portuguese population reported providing informal care (9.6 % of men and 14.6 % of women) compared with 10.3 % in the EU-27 (8.6 % of men and 11.7 % of women). More importantly, 30.6 % of the Portuguese informal carers did so for more than 20 hours a week (23.6 % of men and 34.7 % of women), compared with 22.2 % in the EU-27 (18.5 % of men and 24.6 % of women).

A study by the OECD identifies Portugal as the country with the second highest (after Greece) **gender imbalance as women make up 70.1 % of informal carers aged 50+** while in the remaining EU-27 Member States covered by the study the percentage varies between 52.9 % and 64.3 % (OECD, 2019b).

[868] GEP-MTSSS, 'Gabinete de Estratégia e Planeamento do Ministério do Trabalho, Solidariedade e Segurança Social (2020)', *Boletim Estatístico*, February 2020.

Also national studies have discovered that the typical informal carer in Portugal is a woman aged 45 or more, with low educational achievement. Fewer than half are employed, although the large majority are of working age.[869] A European study concurs the latter finding noting that only 52 % of Portuguese carers aged 18 to 64 were in employment, which is much lower than the EU-28 average (61.5 %).[870]

According to a national study, the association 'Cuidadores Portugal' estimated that without informal carers, around 80 % of older people and dependent people would be institutionalised and that the work performed by informal carers would represent around EUR 4 billion/year (Teixeira et al., 2017). Comparing with Eurostat estimates of the GDP in Portugal, this would mean that the work done by informal carers would be equivalent to approximately 2 % of the Portuguese GDP.

As mentioned above, a formal status for informal carers was recently approved, including a set of **support measures**. Capacity-building and training measures as well as respite offers, through the referral of the cared-for person to residential care or home care services, are among that set of measures (see Section 3).

## 2.4 Financial sustainability

As mentioned above, in 2019 **public spending on LTC in Portugal stood at 0.4 % of GDP**, which is significantly below the EU-27 average (1.7 %). According to the the 2021 Ageing Report[871] spending in Portugal is expected to rise to 0.5 % in 2030 and 0.8 % in 2050, below what is expected within the EU-27: 1.9 % and 2.5 %, respectively.

Public spending on home care represented 44.2 % of total public spending in 2019 and is expected to increase only slightly in the medium- to longer-term to 44.6 % in 2030 and to 45.7 % in 2050. Public spending on residential care is expected to decrease slightly from 55.1 % in 2019 to 54.8 % in 2030 and to 53.9 % in 2050. It should be mentioned that the relative weight of home care and residential care in Portugal is contrary to the situation in the EU-27 as, in 2019, their respective figures were 25.5 % and 48.1 %.

In 2019, social care received a lower share of public spending on LTC than health systems – 0.2 % and 0.3 % of GDP, respectively. Convalescence beds for intensive rehabilitation up to 30 days are funded entirely via the Ministry of Health. Medium-term beds between 31 and 90 days are funded by both the Ministry of Health and the Ministry of Labour, Solidarity and Social Security (MTSSS). Long-stay beds for care beyond 90 days are funded by both ministries but with greater contribution from the MTSSS (OECD, 2019a).

Also, in 2019, public spending on cash benefits accounted for only 0.7 % of total public spending in Portugal, which represents a major difference to the EU-27 where it accounted for

[869] E.g. Teixeira, A. R., Alves, B., Augusto, B., Fonseca, C., Nogueira, J. A., Almeida, M. J., Matias, M. L., Ferreira, M. S., Narigão, M., Lourenço, R. and Nascimento, R., *Medidas de intervenção junto dos cuidadores informais - documento Enquadrador, Perspetiva Nacional e Internacional*, 2017.
[870] Zigante, V., *Informal care in Europe: Exploring Formalisation, Availability and Quality*, London School of Economics and Political Science and European Commission, 2018.
[871] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

26.4 %. The very low public spending on cash benefits in Portugal is expected to increase in the near future considering the recent approval of a formal status for informal carers, including a cash benefit and support measures (see Section 3).

As mentioned above, the work performed by informal carers was estimated to be approximately 2 % of the Portuguese GDP. This means that, assuming the exercise of monetarisation and figures as accurate, informal care would roughly represent 80 % of costs associated with LTC and public spending the remaining 20 %.

The approval of a formal status for informal carers, including a cash benefit and support measures (see Section 3), is expected to provide some new evidence on the financial costs of informal care. However, for the time being, it is uncertain how will expenditure will evolve. It seems certain, in any case, that expenditure needs will be rising and also that gender differences will be present. As seen in Section 2.3 women provide substantially more informal care than men and for an increased number of hours.

Evolution of expenditure should be carefully followed-up. As emphasised by the OECD, 'the Portuguese LTC system is under high pressure to change the way it operates. Financial sustainability is under threat, with many providers operating under tight budgets. The lack of funding, contributes to high waiting lists and considerable out-of-pocket contributions' (OECD, 2019a, p. 69).

### 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Studies in recent years have emphasised that the network of basic care and the rights allocated to those caring for a dependent relative are much more developed when this relates to children rather than adults.[872] The situation of those of working age in need of LTC may be somehow more difficult as most LTC responses are addressed to older people and/or define the older population as priority target, which translates into preferential access, but for RNCCI access is not prioritised by age, but by needs. However, this does not seem to represent a prominent issue for debate in Portugal. Moreover, it should be mentioned that the recently approved formal status for informal carers does not establish any age limits, thus covering children, the working age population and older people.

## 3 REFORM OBJECTIVES AND TRENDS

The relaunching of the RNCCI, including the presentation of a development plan and the decision to expand the network in terms of mental healthcare and paediatric care took place before the period under scrutiny in this section (1 January 2017 – 1 July 2020). In recent years, there was growing concern about the need to develop support measures for informal carers and/or to create a new status for them. Various initiatives have been carried out,

[872] E.g. Casaca, S. F., Perista, H., 'Ageing and older workers in Portugal: a gender-sensitive approach' in: Áine Ní Léime et al. (eds), *Gender, Ageing and Extended Working Life. Cross-national perspectives,* The Policy Press, Bristol, 2017, pp. 137-156.

especially since 2016, culminating in the **approval of a formal status for informal carers** through Law 100/2019, of 6 September.[873]

The law differentiates between two types of informal carer: principal and non-principal. A principal informal carer is a family member living in the same household as the person being cared for, providing care on a permanent basis without remuneration. A non-principal carer is a family member caring on a regular but non-permanent basis, with or without remuneration.

The status establishes a **set of rights** for the informal carer including the right: a) to have their fundamental role acknowledged; b) to receive training and follow-up; c) to receive information from health and social security professionals; d) to be provided with information regarding good practice in the capacity-building, follow-up and counselling of informal carers; e) to receive psychological support from the health services; f) to benefit from respite periods; g) to receive an allowance (means-tested; only for principal informal carers); h) to reconcile care with professional life (only for non-principal informal carers); i) to be eligible for the status of working student; and j) to be consulted about public policies aimed at informal carers.

The law also describes the **supporting measures** the informal carer is entitled to, including: a) an identified health professional as a contact reference; b) counselling, follow-up, capacity-building and training in the development of caring skills; c) active participation in the elaboration of a specific intervention plan for the person they care for; d) participation in self-help groups of informal carers, to be created by the health services; e) training and specific information from health professionals; f) psychosocial support, in conjunction with the contact reference health professional; g) counselling, information and guidance, as well as information regarding the most suitable services and referral when justified; and h) information and referral to support networks, with an incentive to maintain home-based care, particularly domestic support services.

Additionally, in order to ensure that the informal carer can enjoy **respite** periods, the following measures may be activated: a) referral of the cared-for person as an inpatient to a long-term care unit; b) referral of the cared-for person to a social support unit or service, particularly to residential care services, on a temporary basis; and c) home care services.

The law states that an **equivalent pay statement** shall be granted to the informal carer who reduces their professional activity to part-time or ceases it completely. In the latter case, the equivalent pay will have a maximum duration equal to the person's entitlement period to unemployment benefit, and will be granted after expiry of the latter.

The approval of a formal status for informal carers and related supporting measures is undoubtedly **important for promoting** their **work-life balance and social protection**. **However, it seems to replicate characteristics already prevalent in the Portuguese social protection system**, some of which became even more evident after the economic and financial crisis. One such characteristic regards the **reliance upon family**, described over the

[873] República Portuguesa (2019b), Lei No 100/2019, de 6 de setembro, Diário da República, 1.ª série — No 171.

years by studies in Portugal and resorting to the term welfare-families.[874] The approved status for informal carers only considers family members, thus excluding, for example, care provided by friends or neighbours.

This option is probably also connected to a second characteristic, the **stringent conditions for eligibility** including strict(er) means-testing. Reports have highlighted, for instance, that due to strict means-testing some benefits such as child benefit, should not currently be considered as aimed at provisioning people in a specific situation in their life such as the birth and raising of a child but rather only the vulnerable or very vulnerable population facing such situations.[875]

The law establishes an **allowance for informal carers**. Only principal carers are eligible for the benefit, i.e. family members living in the same household as the person being cared for, providing care on a permanent basis without remuneration. The benefit is means-tested and takes into account not only the carer's household income but also the eventual amount of dependency supplement received by the person cared for. In order to be eligible, the household's equivalent income (OECD scale) must be lower than 1.2 times the IAS (EUR 526.57/month, in 2020). It cannot be cumulated with unemployment and sickness benefits, or with most pensions. The exception regards old-age early retirement pensions that suffered a reduction of at least 20 % after the reduction rate and/or the sustainability factor (see Section 1) have been applied. Additionally, the pensioner must demonstrate that, by the time they claimed the pension or up to 12 months after that date, they were part of a household with a beneficiary of the dependency supplement. The benefit is differential, i.e. its amount corresponds to the difference between the amount of the IAS and the amount of the carer's income. The amount of the benefit may be increased by 25 % when the carer is registered in the voluntary insurance scheme as a means of covering the costs with that scheme of social protection.

The amount of dependency supplement received by the person cared for, as well as the amount of the attendance allowance, provided in cases of disability are not included in the calculation. However, they are considered for establishing the amount of the allowance for informal carers. In this case, they are considered along with the carer's personal income which also includes for example, housing allowances. The benefit is differential and has the IAS as a ceiling, which means that its amount results from the difference between the IAS and the carer's monthly income.

Finally, it should be mentioned that the approved status does not bring additional holidays to the informal carer or an entitlement to days of absence from work (e.g. to accompany the cared-for person to a medical appointment).

The COVID-19 pandemic does not seem to have affected the LTC system significantly. As with other sectors, specific guidelines were issued. However, no reforms in the sector,

[874] E.g. Portugal, S., '*Famílias e Redes Sociais - Ligações fortes na produção de bem-estar, Almedina, Coleção CES - Série Políticas Sociais*', 2014.
[875] E.g. Perista. P., Perista, H., Cardoso, A., *ESPN Country Profile 2018/2019 − Portugal, Lisboa, CESIS/LISER/APPLICA/OSE/DGEmployment, Social Affairs and Inclusion*, unpublished and confidential to the European Commission, 2019.

deriving from the impact of the disease, are devisable. For example, on the 27th of May 2020, only 39 cases (i.e. 0.12 % of the total number of cases registered to that date) had been registered in 14 out of the 359 units of the RNCCI.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

Portuguese LTC care is expected to be confronted with significant increased demand in the coming decades. As seen above, there is still a deficit regarding the access to the publicly-funded formal LTC system for older people, but improving. With regards to informal care, recent changes are deemed to represent a positive development although their full impact remain to be assessed. Within this framework, the following policy opportunities seem relevant in order to boost opportunities for addressing LTC challenges:

- widening access and affordability to formal LTC in order to ensure that large segments of the population are no longer excluded;
- ensuring further improvement of the status of informal carers and that the over-reliance on family members (especially women) for care provision is not perpetuated;
- ensuring that the reconciliation of care with professional life envisioned by the formal status for informal carers, including greater flexibility in working schedules (e.g. starting and finishing times, establishment of a bank of hours, concentrated working schedule, incentives for tele-working) in order to facilitate the caring needs of workers (bearing in mind possible gender impacts);
- ensuring a concrete definition of the quality framework for informal care and its enforcement along with the similar framework for formal care;
- revising entitlement to LTC benefits, especially cash benefits, ensuring a closer linkage to the level of dependency rather than focusing excessively on means-testing criteria;
- revising the amount of LTC cash benefits;
- granting tax benefits to those taking responsibility for caring for their relatives;
- developing a process of systematic monitoring and evaluation of public policies in the field, including ex-ante assessments.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 10.6 | 10.3 | 10.1 | 9.4 |
| Old-age dependency ratio, 2019 | | 26.6 | 33.9 | 43.1 | 62.8 |
| Population 65+ (in millions), 2019 | Total | 1.9 | 2.2 | 2.6 | 3.2 |
| | Women | 1.1 | 1.3 | 1.5 | 1.8 |
| | Men | 0.8 | 0.9 | 1.1 | 1.3 |
| Share of 65+ in population (%), 2019 | | 17.7 | 21.8 | 26.2 | 33.7 |
| Share of 75+ in population (%), 2019 | | 8.1 | 10.5 | 13.2 | 19.6 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.3* | 20.6 | | |
| | Women | 21.0* | 22.3 | 23.2 | 25.0 |
| | Men | 17.2* | 18.5 | 19.4 | 21.4 |
| Healthy life years at the age of 65, 2018 | Total | 6.4* | 7.3 | | |
| | Women | 5.8* | 6.9 | | |
| | Men | 7.1* | 7.8 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 831.0 | 905.2 | 976.3 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 492.9 | 582.5 | 733.2 |
| | Women | | 313.7 | 368.9 | 465.8 |
| | Men | | 179.1 | 213.6 | 267.3 |
| Share of potential dependants in total population (%), 2019 | | | 8.1 | 9.0 | 10.4 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 21.8 | 21.8 | 23.3 |
| Share of population 65+ in need of LTC** (%), 2019* | | 34.7 | 32.6 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 1.2 | 1.2 | 1.4 |
| Share of population 65+ receiving care at home (%), 2019 | | | 0.6 | 0.7 | 0.8 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.3 | 0.3 | 0.4 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 8.6 | 8.8 | 9.4 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 1.6 | 1.6 | 1.6 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 37 | 38.9 | | |
| | Women | 37.9 | 39.0 | | |
| | Men | 33.4 | 38.6 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 6.5 | 6.4 | | |
| | Women | 7.3 | 7.3 | | |
| | Men | 5.4 | 5.1 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 30.8 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 7.4 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | - | - | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | - | 0.8 | | |
| | % Women | | 95.8 | | |
| Share of population providing informal care (%), 2016 | Total | | 12.3 | | |
| | Women | | 14.6 | | |
| | Men | | 9.6 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 30.6 | | |
| | Women | | 34.7 | | |
| | Men | | 23.6 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.5 | 0.4 | 0.5 | 0.8 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.5 | 0.4 | 0.8 | 3.0 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 31.6 | 55.1 | 54.8 | 53.9 |
| Public spending on home care as % of total LTC public spending, 2019 | 67.7 | 44.2 | 44.6 | 45.7 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 0.7 | 0.7 | 0.6 | 0.4 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.2 | 0.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.4 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.1 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.3 | 0.3 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# ROMANIA

***Highlights***

- *In Romania the proportion of older people, with respect to the old-age dependency ratio is still below the EU-27[876] average, but is increasing faster than in most of the Member States.*
- *While long-term care (LTC) is defined in the Social Assistance law, there is not a specific LTC insurance scheme in Romania. Different social protection schemes target different groups, which sometimes overlap. Thus, a cross-cutting definition for ensuring equitable basic support to all those with LTC needs would be beneficial.*
- *Cash /in-kind benefits to the person in need of care or to the carer are directed towards people with disabilities[877], and, in some cases towards patients. A more general cash/in-kind support, especially for informal carers of older people, is needed.*
- *LTC social services – institutional, community-based and homecare - are decentralised, and, as a consequence, remained underdeveloped and are unevenly spread across communities, depending on the administrative and financial capacity of local authorities. Access is uneven and affordability of LTC services for older people low. Financially sustainable decentralisation is a priority.*
- *In 2019, quality standards have been adopted, yet their enforcement was rather administrative, with no regard to professional ethics. Quality standards need professional enforcement, control and public transparency. Sub-county level resource centres would benefit from a professional approach.*
- *LTC services are biased towards residential care, and community-based services are unprepared to support a policy of prevention of institutionalisation. Formal in-home carers benefit from minimal support, yet informal carers do not benefit from any support. A strategy to develop sustainable non-residential services needs both professional and financial support.*

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The LTC system in Romania is expected to face increasing pressure in the coming years especially due to the ageing population that will probably translate into higher demand and

[876] EU-27 refers to the current 27 Member States of the European Union.
[877] Older people who have chronic diseases, who are terminally ill or have multiple comorbidities can be assessed to be classified with a degree of disability. In this way, they can benefit from a care allowance usually granted to a member of their family.

into less financial resources deriving from taxes in order to ensure future supply of LTC. The median age of the Romanian population, and the proportion of people aged 65 and more, while both still below the EU-27 average[878], increased during 2008-2018 at a higher pace compared to the EU-27 average value; the increase in the proportion of the population aged 80 and over was even higher, the highest increase across the European Union. This signals an accelerated ageing process within the population. Overall, the old- age dependency ratio (65 years and over to 15-64 years old) was in 2019 still below the European average (28.1 %, compared to 31.4 %), yet the rate that it is increasing is higher than at EU-27 level[879].

Romania is among the Member States with the lowest life expectancy at the age of 65 years; in 2019, its value was 16.9 years for the entire population, with men two years lower than this and women 1.7 years higher. Overall, its relative position slightly worsened in 2019 compared to 2010, as the increase rate in life expectancy at 65 years was slower than that of other Member States with similar life expectancy; in addition, the gap in life expectancy between men and women increased (in absolute and relative terms[880]). The proportion of healthy years, the number of absolute years of life expectancy at 65 years, places Romania again among the countries with the lowest values (in 2018, 37 %, compared to 50 % at the EU-27 level). Romanians at 65 years could expect, in 2018, on average, 6.1 years of healthy life, an improvement of 0.6 years, compared to 2010; yet this is still 62 % less than the EU-27 average number of healthy years.

In 2019, the population aged 65 years old and over in Romania was about 3.6 million people, this is 18.5 % of the total population, compared to 15.4 % in 2008. As the old-age dependency ratio increased, so did the regional disparities with an older population in the South-Oltenia and South-West-Muntenia regions and a younger population in the North-Eastern part of Romania (the region with the highest poverty rate as well). While in 2019 there was a difference in the old-age dependency ratio between rural and urban areas, the gap had decreased significantly compared to 2008, from 60 % to 13 %[881]. The Ageing Working Group (AWG) reference scenario[882] identifies, for 2019, a proportion of 6.4 % of the population as potentially dependent[883] and this proportion is expected to reach 7.3 % in 2030 and 8.9 % in 2050. In absolute numbers, this will translate into an 11 % increase of the number of people which will be potentially dependent. The increase of potentially dependent people aged 65+ will be much larger (+ 40 %), from 763,600 to 1,070,100 people.

[878] 42.5 years, respectively 18.5 % in 2018, compared to 43.7 years, respectively 20.3 % at the EU level (Eurostat, demo_pjanind)
[879] All data used in the text come from Section 5 'Background statistics' unless explicitly stated otherwise.
[880] While in 2010 the difference in life expectancy at 65 years between men and women was 3.4 years, slightly less than the EU average value, in 2018 the difference increased to 3.7 years, above the EU average. The gender gap increased from 21 % in 2010 to 22 % in 2018, placing Romania above the EU average.
[881] The data source is TEMPO-online database (National Institute for Statistics), POP108B, http://statistici.insse.ro:8077/tempo-online/#/pages/tables/insse-table
[882] assuming no changes in the structure of benefits' provision and similar cost profiles
[883] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070),* 2021.

## 1.2 Governance and financial arrangements

In 2011, Romania adopted a legal definition of LTC (L292/2011) as 'caring for a person who needs help for more than 60 days to perform the basic and instrumental activities of daily living'. Personal care services are aimed at dependent people who, as a result of the loss of functional autonomy due to physical or mental causes, need significant help to perform the usual activities of daily living.

Long-term care can be provided at home, in residential centres, day centres, at the home of the person who provides the caring and within the community.

There is not a specific LTC insurance scheme. Different social protection schemes target different groups, which sometimes overlap.

In conformity with the Social Assistance Law no. 292/2011, elaboration of public policies, programmes and national strategies in the field, regulation, coordination and control of their application, as well as evaluation and monitoring of the quality of social services, these are under the responsibility of the central public administration authorities.

The policies on social assistance, on older people protection are developed by Ministry of Labour and Social Protection. The **policies targeting people with disabilities** are developed by the National Authority for Persons with Disabilities, Children and Adoptions are subordinated to the Ministry of Labour and Social Protection. Organisation, administration and provision of social services are under the responsibility of local public administration authorities, responsibilities that may be outsourced to the non-governmental sector, religious institutions, other individuals and legal entities under public or private law, under the law.

Most of the cash benefits come from the state budget, with the exception of the salary of personal assistants (formal carers) of people with severe disabilities, who are employees of the local authorities and paid from the local budgets[884]. In 2018-2019, the coverage of cash disability benefits varied between 88 % and 90 %. In fact, in 2018, the expenditure of cash/in-kind benefits with disabilities, supported from the state budget, accounted for 28 % of all expenditure with social benefits from the state budget. Residential care and community-based services (e.g. day care centres, recovery ambulatory centres, respite and crisis centres) are mainly financed from the county-level budgets, with support from the state budget[885], specifically from VAT.

LTC services are provided either by public social assistance agencies or subcontracted to private accredited social service agencies and are under the financial responsibility of local authorities.

By law, financing social services for older people is made on the principle of subsidiarity and of dividing responsibility between the central and the local public administrations. LTC is financed by funds allocated from local budgets and the state budget.

[884] Despite the fact that the law stipulates that salaries are supported from the state budget and funds should be transferred, upon request, to local budgets, problems arose constantly during the last five years; in 2019, the state budget law did not specify this expenditure, thus leaving most of the small/rural communities unable to pay the salaries and uphold employment of these category of carers.

[885] according to the legislation up to 90 % of the current expenditure, yet transfers vary and are not predictable

1. The state budget covers the costs of investments and repairs for various social services in disadvantaged areas, national programmes to increase the quality of services for older people.
2. Local budgets cover operational costs for residential care homes, community services and home care in their territorial responsibility.
3. Beneficiaries have to co-finance the costs, depending on the type of service they receive (home or residential care) and the value of their income.
4. Informal caregivers receive certain types of benefits.
5. Subsidies for non-governmental organisations

The law regarding the social assistance of older people[886] identifies funding sources for both residential and non-residential community-based services (day care centres, rehabilitation ambulatory centres, in-home care) extra-budgetary funds of the local budgets and subsidies from the state budget (up to 10 % of the monthly maintenance expenses), when extra-budgetary funds of the local budgets are insufficient; there is a small contribution from the state budget (from general taxes), in the form of subsidies of non-governmental social service providers (Law no. 34/1998) and some support for capital investments, channelled through the MLSP in the form of National Interest Programmes.

During 2019 and 2020, the Ministry of Labour and Social Protection carried out a national interest programme through which it finances from the state budget the development of community services at home for dependent older people, to the tune of 25,184,320 lei (EUR 5,246,666)[887].

In addition, there is also an out-of-pocket contribution for LTC services for dependent older people. Beneficiaries are financially responsible for their maintenance/ homecare services expenses, up to 60 % of their own income; the remaining expenses are the financial responsibility of the legal supporters of the dependent older people (direct family, children/grandchildren/nephews), as long as their income per family member is higher than the minimum net salary. Any uncovered costs by the beneficiary or family is covered by local authorities.

Homecare services require a contribution of the beneficiary, unless these represent social reintegration/ prevention of social exclusion services; older people who have a minimum income guarantee[888] or have an income lower than the minimum social pension[889] and have no legal supporters, or their supporters have an income below the thresholds specified above, receive services free of charge. All other dependent people have an obligation to pay a contribution, established by the local councils, according to their income and the costs of

[886] Law 17/2000 modified by the GEO 34/2016
[887] GD no. 427/2018 for the approval of the program of national interest 'Community home services for dependent elderly people' and of the program of national interest 'Increasing the capacity of public social assistance services in some administrative-territorial units'
[888] In April 2020, the threshold for the minimum income guarantee is 142 Lei (i.e. EUR 29) for singles
[889] In April 2020, the minimum social pension is 704 Lei (i.e. EUR 146), until 2021 when the new pension law 127/2019 will take effect and will tighten the benefit to the social reference index and the length of the contributory period

rendered services. In the case of residential care and other community-based services, all beneficiaries who have an income, regardless of its size, will have to pay a contribution, up to 60 % of their income, but no higher than the monthly living expenses[890] for the particular service. The remaining uncovered part of the monthly living expenses is payable by the legal supporters of the beneficiary, if there are any, and if these have an income per family member higher than the net minimum salary[891]. There is no cash benefit for dependent older people.

***Certified 'invalidity'***, reflecting a partial or total loss of work capacity (with three degrees of invalidity), falls under the responsibility of the ***social insurance system, through the National Public Pension House (NPPH)***, and results in invalidity pensions and medical support care and rehabilitation, provided through its own health care services and networks (National Institute for Recovery of Work Capacity, NIRWC). Invalidity pensions and specialised health care rehabilitation programs are paid from the Social Insurance Fund (from the social contributions for pensions).

The ***health insurance system,*** through the county-level Health Insurance Houses, ***targets people with chronic illnesses (ECOG3 and 4 health status[892])*** and offers homecare (medico-social services) through its subcontracted service providers. Homecare services are offered for at most 90 days /year, and covered, on a service-day-based standard cost, from the Social Health Insurance Budget, through the county level Health Insurance Houses. In addition, the health insurance budget supports any necessary medical services to those older people identified as being eligible for homecare services by the local authorities.

While there is no systematic data regarding the size of the informal sector, survey data suggests that a significant share of homecare services are provided informally and most dependent older people who are still living at home rely on family members or other informally hired, mostly un-specialised help.

## 1.3 Social protection provisions

Entitlement to benefits and services granted to people in need of LTC is granted by the assessed need and its degree of urgency/ severity – i.e. **disability** (severe/ marked/moderate/mild[893]), **special educational needs**[894], **dependency of older people** (IA-IB-IC, IIA-IIB-IIC, IIIA-IIIB)[895], **invalidity** (degree I/ II/III)[896], **ECOG health performance**

[890] Law no. 18/2018, amending law no. 17/2000 regarding the social protection of older people; the monthly living expenses are established by the local authorities, and cannot be less than the minimum standard cost established for this type of services by the government; in April 2020 the minimum cost for the homes of elderly is set at 23,784 Lei (i.e. EUR 4291)/year/beneficiary (https://www.servicii-sociale.gov.ro/ro/persoane-varstnice).

[891] The share of expenditure covered by beneficiaries and/or their legal supporter in privately administrated homes for older people was 79 % in 2017, while the share was lower in public administrated homes (29 % in those homes administrated by local councils, respectively 12 % in those administrated by county-councils); overall, the share of expenditure paid by these amounted in 2017 to 50 % (National Institute for Statistics, TEMPO-online database, ASS113C, ASS113D, ASS113E).

[892] The acronym stands for Eastern Cooperative Oncology Group, who developed a set of criteria for independent/autonomous health status of patients.

[893] Certification of 'handicap' in the Romanian legislation; the **complex evaluation commissions** organised at the level of the county-council issue these certifications. Reassessment periods are established by the Commission, based on the disability

[894] The assessment is done by the **professional and educational orientation commission** (organised at the county level Educational Assistance and Resource Centre, under the responsibility of the Ministry of Education

[895] **Dependency of older people** is 'a result of the loss of autonomy due to physical, psychical or mental causes which require significant help/ assistance to perform basic day-to-day activities' (GD 886/2000 for the approval of the national

**status**[897]. Most of the benefits and services are granted based solely on the assessment of need, measured as shown above. Yet the services targeting dependent older people require income-tested contributions from the beneficiaries, or their legal supporters.

**A variety of cash benefits** target two categories of people in need of LTC due to disabilities or work incapacity: (a) people with (severe, marked and moderate) disabilities and (b) people who have lost their capacity to work (assessed with a degree of invalidity). Adults with disability receive a benefit (for severe and marked disabilities) and a complementary budget (for severe, marked and moderate disability), both differentiated according to the degree of disability. In addition, a monthly food payment for people with HIV/AIDS is granted. About 40 % of those receiving disability benefits are older people[898]. People who have lost their capacity to work receive an invalidity pension and an indemnity for companions. All categories in need of LTC benefit of some gratuities.

**Regarding carers**, the following categories are distinguished and **covered with benefits**: (a) carers of children with disabilities, (b) companions of severely visual impaired people, (c) personal assistants or companions of people with severe disabilities, (d) family members caring for (semi)dependent older people. Employment is offered to all carers of people with severe disabilities and part-time employment to those assisting dependent older people. Alternatively, people with severe disabilities can opt for an indemnity, equivalent to the net salary of a personal assistant. Transportation costs and costs related to accompanying a person with severe disabilities or a child with disabilities in the hospital or medical treatment facilities are also covered for personal assistants or companions.

## 1.4 Supply of services

In 2019, 846,000 people were certified with a disability (of which 89 % with severe or marked disabilities); out of these, 360,000 were 65 years and over (i.e. 43 % of those certified with a disability and 10 % of the entire population of 65 years and older). Overall, only 2 % of all certified people with disabilities live in residential care, and only 1 % of the older people with disabilities[899]. While coverage with benefits is high, the coverage of people with disabilities living with their family with services is extremely low; only 0.2 % of these benefited, in 2019, of (specialised) care in day centres, recovery ambulatory centres or crisis/

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evaluation test. **Local authorities** have the responsibility to set up a commission to assesses both the medical condition and the income level of older people. The Commission is composed of at least one specialist medical doctor in gerontology and two social workers, but it can and is recommended to include representatives of NGOs who provide service to older people, representatives of religious charitable organisations.

[896] **Invalidity** is defined a functional deficiency with impaired work and eventually self-service capacity due to work accidents or professional diseases or to a regular diseases or accidents unrelated to work; the **National Public Pension House**, through the **National Institute for Medical Expertise and Recovery of Work Capacity**, organizss the assessment and recovery activities. Work capacity has to be reassessed between one and three years, depending on the recommendations of the Commission.

[897] **ECOG 3/4 health performance status** – the person is unable to perform household activities, is immobilised over 50 % of the time or is completely immobilised in bed or wheelchair, needs support / or is totally dependent on others for basic personal care (hygiene, eating and/or stand up).

[898] Ministry of Labour and Social Protection, Statistical Bulletin, *Persons with Disabilities*, http://mmuncii.ro/j33/images/buletin_statistic/dizab_2019.pdf. According to official data, 98 % of the persons with disabilities living with theie family receive one or more benefits; yet 43 % of the people with disabilities living with their family were, in 2019, 65 years and older

[899] Ibid.

respite centres or homecare. The proportion of community-based services is only a mere 12 % of all public care centres, while its target population is 47 times more numerous than that in residential care. Homecare services are barely available, with a mere 89 beneficiaries, on average, in 2019[900]. While data are not available, interviews with local officials suggest that the proportion of private providers of services targeting disability was, in 2019, still low compared to the current needs; and this, despite the increased and targeted financing to support de-institutionalisation of adults with disabilities.

LTC for dependent older people is biased towards services, especially residential services. In 2020[901], 622 residential homes are functioning (122 public services, 500 private services). At the same time, there are 260 licensed home care social services (71 public, 189 private ones)[902].

In 2016, medical homecare services for those with an ECOG 3 and 4 health performance status were provided to 45,200 people for an average of 28 days/year (by a total of 498 service providers).

While LTC care services are biased towards institutional services, the number of beds in nursing and residential care facilities per 100,000 inhabitants (Section 5) in Romania, in 2017, was among the lowest across EU-27 (i.e. 198.61 beds per 100,000 people), signalling an underdevelopment of LTC services in general. In 2016, the proportion of households in need of LTC not using professional homecare services for financial reasons was 70.1 %, by far the highest proportion among the Member States.

In 2019, Romania had, the lowest proportion of self-reported use of home care services across the EU-27 (2.9 % compared to 8.4 %, the EU-27 average value, see Section 5). This is consistent with the very low proportion of people providing informal care, (2.3 % in 2016, by far the lowest level across the EU, see Section 5).

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

As shown in Section 1.3, the coverage with cash benefits targeting either people with disabilities or those assessed as invalids is high (i.e. 89 %, in 2019). Thus, about 724,000 people with moderate, marked or severe disabilities benefited from one, two or three benefits, depending on the level of disability. The high coverage is due to the fact that benefits are paid from the state budget. Affordability of residential and non-residential services for people with disabilities is high (as these are provided free of charge), yet access is limited due to the insufficient number of service providers, especially of community-based services.

[900] Table 9, Statistical Bulletin – Persons with Disabilities, Ministry of Labour and Social Protection, available at http://mmuncii.ro/j33/images/buletin_statistic/dizab_2019.pdf
[901] available by 7 October 2020
[902] Ministry of Labour and Social Protection, *The National Register of Licensed Social Services,* http://mmuncii.ro/j33/index.php/ro/2014-domenii/familie/politici-familiale-incluziune-si-asistenta-sociala/4848

Residential and community-based services, including homecare services, for dependent older people, are scarce as well (see Section 1.1 and 1.4.); the availability of these services is rather low, and their provision and financing depends, to a large extent, on the administrative and financial capacity of the local authorities[903]. Yet the problem regarding their availability is surpassed by the incapacity of the beneficiaries and their families to financially afford these services. High contributions make Romania the country with the highest proportion of people who claim financial reason as a barrier to professional homecare (i.e. 70.1 % compared to the EU-27 average of 35.7 %, in 2016, see Section 5).

In private residential homes for older people, contributions of beneficiaries and their legal supporters make up for 78 % of the total current expenses, while in public residential care contributions account for a smaller proportion (12 % for those financed from county budgets and 29 % for those financed from local budgets[904]). The decentralisation of these services led to inequality of access between wealthier communities and less wealthy ones, between big cities and rural areas, as provision and affordability depend both on the administrative and financial capacity of the local authorities.

## 2.2 Quality

The quality of LTC social and socio-medical services is regulated by the law regarding the quality assurance of social services (Law 197/2012). In 2019, quality standards have been revisited for each type of social service and each category of beneficiaries[905]. The Social Policies and Services Directorate of the MLSP is in charge of designing the minimum quality standards for social services for dependent older people and the accreditation of all public and private service providers. The minimum quality standards cover residential care (residential centres as well as protected dwellings), community-based care (day centres, mobile team interventions) and homecare (Order of the MLSJ 29/2019). The National Authority for People with Disabilities (under the MLSP) is in charge of elaborating on the standards and the accreditation of specialised social services for adults with disabilities (Order of MLSJ 82/2019), differentiated according to the type of service provided. Standards for carers do apply for the (professional) personal assistants for the people with severe disabilities (Law 448/2006 and EGO 51/2017). The county level deconcentrated agencies of the National Agency for Payments and Social Inspection (NAPIS) are in charge of the assessment of providers and social services (for accreditation purposes) and with the monitoring/enforcement of these quality standards. The Social Inspection can also undertake unannounced control visits and conduct inquiries when problems are signalled; yet it is not responsible for providing a systematically monitoring of service providers or social services.

Informal carers are legally defined by the social assistance law, but no quality standards are available for this category and, as a consequence, also no systematic support from the public

[903] In 2017, the number of people on the waiting list of the public and private homes for older people represented between 9 % and 20 % of the number of current beneficiaries (according to the Tempo-online database, ASS113C, ASS113D, ASS113E)
[904] Data for 2017, according to the National Institute for Statistics, TEMPO-online, ASS113C, ASS113D, ASS113E
[905] According to the law, quality standards cover the following areas: social service provision, relationship between provider and beneficiaries, beneficiaries' participation, relationship between providers and community actors, development of human resources

institutions. There is a need for training and sharing experiences between carers, yet there are no support services allowing these to join support groups or to attend training sessions.

Medico-social and medical services are directly regulated in terms of standards through the medical profession (professional commissions) and the National Authority for the Management of Health Service Quality (which accredits medical services based on the International Standards of Quality Assurance system). Quality standards for medical services cover, indirectly, all those medical services provided to those who are chronically ill/ temporary unable to work. Yet medical staff and medical procedures in social or socio-medical services elude any direct quality control and professional supervision.

## 2.3 Employment (workforce and informal carers)

In Romania, the proportion of older people that report using in-home care (2019) was 2.9 %, the lowest across the EU. In 2016, 70.1 % of the population claimed financial reasons for not using professional in-home care. With 1 LTC worker per 100 older people (65 years and over) in 2016, compared to 3.8 for the EU-27 average, Romania is among the countries with the lowest number (OECD, 2019[906]).This situation has its roots in the limited financial public support for in-home professionals or community-based services and in the shortage of professionals and people working in this sector. In 2018, according to the National Institute for Statistics, 239,000 people (more than 1 % of the population) left for work abroad for more than 12 months. Available information suggests that a significant share of these are working in health care services (medical and/or homecare). The OECD report (2019) points out that Romania is among the top 20 countries to provide LTC workforce to OECD countries. For example, Romanian nurses account for half of all foreign trained Italian nurses (OECD, 2019, p.24).

Jobs in the LTC system have become more attractive since 2018 after a law[907] passed in 2017 stipulated a phased increase of all salaries in the public sector until 2022. Only salaries of doctors and medical staff were increased at a faster pace. Thus, non-medical personal care workers in the socio-medical sector were put, even more[908], at disadvantage; the minimum gross monthly earnings is about two times lower, on average, for personal care workers, according to the OECD (2019) report, approximately EUR 400 (30 % above the minimum wage) in 2017. While no specific educational degree is required for personal care workers (with the exception of nurses, with a technical degree after high school), these are required to undergo a continuing training programme (to be provided by employers, see OECD report, 2019, pp. 35-39).Two levels of qualification are established for LTC non-medical carers, accomplished through 360 to 420 training hours for a level 1 qualification, 720 training hours for a level 2 qualification. While Romania put in place some policies for recruitment and retainment of the LTC workforce (training programmes provided free of charge through the employment programme, special financial incentives to take up/ retain jobs in the sector,

[906] OECD, *Measuring social protection for long-term care in old age. Final Report*, 2019. https://www.oecd-ilibrary.org/social-issues-migration-health/measuring-social-protection-for-long-term-care_a411500a-en
[907] Law 153/2017.
[908] Differences in earnings between personal care workers and nurses were already high in 2017, see OECD, 2019, p.43, fig.2.14

stimulating part-time and voluntary work contracts), earnings are still too low to compete with western Member States absorbing foreign workers in the LTC sector; according to a Romanian job website[909], in 2019, LTC employees were paid in Romania between 1 and 1.5 times the minimum salary per month (i.e. 2080 Lei, i.e. about EUR 430), while the salaries in the UK, for the same job, for Romanian workers ranged between £1500 and £2000 (i.e. EUR 1660 and EUR 2218).

The COVID-19 pandemic will most probably reverse the trend to some extent, increasing the availability of the LTC workforce, especially the non-medical staff, to take up local jobs; many of these were working informally, and found themselves without jobs during the pandemic crisis. Romania has witnessed a massive return of its migrant workforce since March 2020. Yet without the support of local and central authorities in providing decent jobs and ensuring professionalisation of this segment (as legally stipulated, yet not really enforced) this favourable momentum will not benefit the Romanian LTC sector. Financial stability for those employed in the sector is vital, along with professional support put in place by public authorities – basic and specialised training modules, a network for help and support to cope with specific issues and ensuring temporary replacements whenever needed. Currently, while the legislation stipulates annual training sessions for professional caregivers and personal assistants of dependent people, local authorities have no capacity to offer and provide these. In 2016, the proportion of people providing informal care was the lowest across the Member States (2.3 %, see Section 5). The imminent economic recession might change this to the benefit of those in need of homecare. Yet some support (in-kind or cash benefits, as temporary relief help, pension credit) for informal carers could provide a significant incentive.

## 2.4 Financial sustainability

As a rule, services financed from county budgets are more developed and financially more stable than those financed from local budgets, as counties have more resources. Not only is there no financial capacity at the local level, but administrative capacity to manage residential services is also low compared to private homes, as can be seen from the higher monthly expenditure per beneficiary in public homes, compared to private ones. While data on expenditure with community-based services for both people with disabilities and dependent older people are not available, and extremely non-transparent, it is safe to assume that the same problems holds true for these as well. Medical homecare, for ECOG 3 and ECOG 4 patients, although paid from the Social Health Insurance Budget, is still underdeveloped and has an extremely low budgetary allocation (in 2018, 0.16 % of the total expenditure with medical services[910]). From the funds allocated to the national health programmes from the state budget and from the health insurance budget, social LTC expenditure was, in 2018, three times lower (0.1 % of GDP) than the health LTC expenditure (0.3 % of GDP, see Section 5).

[909] https://bundeangajat.olx.ro/ce-presupune-meseria-de-ingrijitor-batrani-la-domiciliu/
[910] Annual report of the National Health Insurance House, http://www.cnas.ro/page/rapoarte-de-activitate.html

The 2021 Ageing Report[911] data on Romania reflects a rather age-related perspective of dependency and public expenditure with LTC, thus emphasising medical and social expenditure is mostly targeted towards older people. The positioning of Romania with regards to the level and structure of expenditure with LTC is therefore influenced by both the age-related perspective and the lack of transparency regarding beneficiaries and the expenditure of LTC services from local budgets. According to the AR 2021 data, Romania had, in 2019, one of the lowest shares of public spending on LTC of GDP, i.e. 0.4 %, increasing to 0.7 % in the reference scenario and 1.7 % in the risk scenario.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

An overwhelming proportion of people certified with disabilities are living with family (98 %, in 2019), compared to those in public residential care. Despite the legislative efforts during the last three years to support de-institutionalisation of adults and children with disabilities, the network of available (specialised) community-based services is mostly missing and if present, it is rather underdeveloped. The number of services is low, currently covering at most 2 % of the population in need, and these are mostly available in large cities. Costs of specialised services are higher and the proportion of private providers lower. Thus, one of the most important challenges for the LTC system is the diversification and increase of financial support for community-based services and networks addressing people with disabilities and especially their formal or informal carers. While people with disabilities in need of LTC is not an age-related group, according to the statistics provided by the MLSP, older people represent 43 % of all people with disabilities, this is about 10 % of the total number of people aged 65 and over.

# 3 REFORM OBJECTIVES AND TRENDS

In 2018, the government approved, in agreement with the social partners, a National Reform Program[912], which explicitly addresses some of the most important challenges of the LTC system, and specifically of those targeting older people, in the context of the implementation of the National Strategy for Promoting Active Ageing 2014-2020. A first priority set by this was the development of community-based services for vulnerable older people or those at risk of poverty. Three projects have been started, with a budget of EUR 1,870,000 (European Fund for Regional Development and state budget). Another line of reform followed by the programme is the prevention of institutionalisation of dependent older people; this policy objective is pursued through two projects (state budget financing) targeting the development, and increasing the capacity, of public community-level and in-home social services. The first project will specifically target the implementation of case management and of the proximity principle for 1000 dependent older people. The second one is targeting about 1000 local administrations and supporting these to develop and manage the provision of social services

[911] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

[912] https://ec.europa.eu/info/sites/info/files/2018-european-semester-national-reform-programme-romania-ro.pdf

in the community, especially in those rural communities without an accredited public social assistance service.

The deinstitutionalisation (e.g. transferring beneficiaries in protected dwellings[913] or to (foster) families, while promoting independent living skills and support services) of people with disabilities has been a significant priority during the last few years; therefore, a significant share of resources was allocated over the last two years (from the state budget and EUR 16,300,000 from the European Fund for Regional Development in the form of National Interest Programmes) for the re-structuring of the existing residential centres and the development of day centres and protected dwellings, in order to promote independent living.

Yet maybe the most important reform in the area of LTC services, and implicitly in the area of age-related LTC services, was the redefinition, in 2019, of the quality standards for all types of social services and beneficiaries. In May 2020, new cost standards for all social services, including residential and in-home care services for older and dependent adults, were adopted (GD 426/2020).

COVID-19 generated a crisis also in the LTC sector, as the social services for dependent older people have proved to be the most vulnerable services across the medical and health care system. As a response, in June 2020, the government launched a support programme for vulnerable groups affected by the epidemic, especially older people, which includes support services, in-home care and a national emergency telephone line. The project will run for six months and has a budget of EUR 18,000,000; it is implemented by the Ministry of Labour and Social Protection and ASSOC, a NGO in the field of social assistance. As most of the COVID-19 cases were clustered around homes for older people or day care centres for older people, bringing to the service the problems related to human resources in the sector. On April 30, 2020 a legislative project has been drafted, which grants care workers the same risk benefits as medical personnel in hospitals during the health care crisis. Yet this is intended only to be a temporary measure. Another consequence of the COVID-19 epidemic, representing an opportunity for the Romanian LTC system, is the return of a significant number of LTC workers from countries were these were working temporarily. While the demand for Romanian care workers within other Member States is beginning to increase again, the return of a trained and experienced workforce could represent an important opportunity for the Romanian LTC sector.

[913] Defined as individual homes for 7-8 people which are living in the community and benefit of a series of support services in order to increase their ability for independent living and their social integration.

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The major challenges of the LTC system in Romania are (a) its fragmentary character without any coordination between the various definitions of and policies addressing LTC needs, (b) the underdevelopment and financially unsustainable public social service system, especially of the community-based and homecare services, in terms of coverage and financing level, (c) inequities of access and affordability of services due to a geographic/ residential reasons and high contributions imposed for beneficiaries and their families, and, (d) the lack of systematic employment-related, professional, in-kind or monetary support for formal and informal carers. The COVID-19 crisis opened up significant opportunities for the improvement of the LTC sector, due to both an increase in public support for addressing the issues which became visible during this period and to the return of a significant, trained and/or experience, workforce from abroad.

A single, cross-cutting definition of dependency, able to assess LTC needs, would benefit this fragmented approach, as it could be linked to priority funding, gratuity of access to services or/and benefits for the carers (disregarding the type of conditions identified within the various systems).

There is a need to identify effective ways to support local authorities to develop sustainable services in the community, by (a) creating strong resource centres at a county or sub-county level to provide expertise and administrative counselling and (b) stipulating compulsory and increased financial support from the state budget for all services targeting dependency.

Increasing support for carers, formal and informal, could be more cost-effective than investing in residential care, and the status and rights of carers could be easily revisited, especially after the pandemic.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 20.6 | 19.4 | 17.8 | 15.5 |
| Old-age dependency ratio, 2019 | | 22.6 | 28.1 | 34.0 | 54.5 |
| Population 65+ (in millions), 2019 | Total | 3.2 | 3.6 | 3.9 | 4.7 |
| | Women | 1.9 | 2.1 | 2.3 | 2.7 |
| | Men | 1.3 | 1.5 | 1.6 | 2.1 |
| Share of 65+ in population (%), 2019 | | 15.4 | 18.5 | 21.8 | 30.6 |
| Share of 75+ in population (%), 2019 | | 6.4 | 8.1 | 10.7 | 16.4 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 16.1* | 16.9 | | |
| | Women | 17.6* | 18.6 | 20.1 | 22.9 |
| | Men | 14.2* | 14.9 | 16.5 | 19.5 |
| Healthy life years at the age of 65, 2018 | Total | 5.5* | 6.1 | | |
| | Women | 5.2* | 5.9 | | |
| | Men | 5.9* | 6.3 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 1,237.8 | 1,295.8 | 1,374.5 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 763.6 | 847.6 | 1,070.1 |
| | Women | | 510.4 | 563.8 | 682.7 |
| | Men | | 253.2 | 283.8 | 387.4 |
| Share of potential dependants in total population (%), 2019 | | | 6.4 | 7.3 | 8.9 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 21.1 | 21.9 | 22.6 |
| Share of population 65+ in need of LTC** (%), 2019* | | 35.0 | 56.5 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 4.7 | 4.9 | 5.3 |
| Share of population 65+ receiving care at home (%), 2019 | | | 6.0 | 6.3 | 6.8 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 50.5 | 51.4 | 54.0 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 0.0 | 0.0 | 0.0 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 70 | 61.6 | | |
| | Women | 71.8 | 63.3 | | |
| | Men | 66.2 | 58.1 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 4.7 | 2.9 | | |
| | Women | 5.7 | 3.2 | | |
| | Men | 3.3 | 2.6 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 70.1 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 9.1 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 140.9 | 198.6 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 1.0 | 1.0 | | |
| | % Women | | 93.3 | | |
| Share of population providing informal care (%), 2016 | Total | | 2.3 | | |
| | Women | | 2.8 | | |
| | Men | | 1.6 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 20.6 | | |
| | Women | | 23.2 | | |
| | Men | | 15.5 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.7 | 0.4 | 0.4 | 0.7 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.7 | 0.4 | 0.6 | 1.7 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 11.7 | 50.0 | 50.4 | 50.8 |
| Public spending on home care as % of total LTC public spending, 2019 | 87.1 | 50.0 | 49.6 | 49.2 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 1.2 | 0.0 | 0.0 | 0.0 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.3 | 0.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.0 | 0.1 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.0 | 0.0 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# SLOVENIA

***Highlights***

- *In Slovenia, there is currently no uniform definition of long-term care (LTC) and no uniform LTC system. There is no single and overarching legislative act in Slovenia that covers LTC. Currently the services which could be classified as LTC are provided within different social protection systems:, the health care system, the social care system, the parental care system, pension system, educational system and disability care system with different governance policies, fragmented and segmented needs assessment procedures, an uneven provision of rights, a lack of coordination and unequal financing of the same needs.*
- *Due to population ageing, the number of older people needing LTC has been increasing. In 2019, 21.3 % of the population aged 65+ received formal LTC in-kind or cash benefits. The share of the population aged 65+ having difficulties in personal care or household activities was 38.8 % (Section 5 'Background statistics').*
- *Total public LTC expenditures amounted to 1.0 % of GDP in 2019. It has been estimated that the LTC expenditure would further increase by 2050, making the system of LTC financially unsustainable, all things being equal.*
- *The affordability of LTC (evaluated by comparing the incomes of older people and the cost of care) has been worsening since 2007. Quality of LTC is difficult to judge as, except for monitoring and minimum standards, there are no quality and safety assurance and strategy at national level.*
- *The burden of care for dependent relatives is due to insufficient supply of formal LTC services at home and long waiting lists for residential care. This is mostly left to informal carers, who are mainly women.*
- *A new draft Act on LTC was in public debate until 5 October 2020. Currently the draft is being debated by The Economic and Social Council of the Republic of Slovenia (ESC)*

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The LTC system in Slovenia is expected to face increasing pressure in the coming years especially due to the ageing of the population that will translate into higher demand and less public and private financial resources to ensure future supply of LTC. The population has been increasing continuously since 2008. From 2008 to 2012, the proportion of older people remained almost stable as the total population growth was high. When it started to decrease

and was lower between 2012 and 2017, the proportion of older people in the total population grew at a faster pace. These trends are reflected in the development of the old-age dependency ratio (ratio between the population aged 65+ and the population aged 15-64). This ratio was 23.3 % in 2008[914] and had been increasing fast since then, reaching 30.5 % in 2019.[915] This is an increase of more than 30 % in the last 11 years, compared to a 22 % increase in the EU-27[916]. Between 2008 and 2019, the average annual growth rate of the old-age dependency ratio in Slovenia was 2.48 as opposed to 1.84 in the EU-27. The highest increase in the old-age dependency ratio was observed between 2016 and 2018. Although the growth rate slowed slightly in 2019, it was still very high.

The number of people who need support in their basic (activities of daily living- ADL) and supporting daily activities (instrumental activities of daily living- IADL) will increase in the next 30 years, and the old-age dependency ratio is predicted to reach the value of 39.2 % in 2030 (close to the EU-27 old-age dependency ratio of 39.1 %). In 2050, the old-age dependency ratio in Slovenia (54.9 %) will be one of the highest in the EU-27 countries. The 2050 values will range from 35.3 % in Cyprus up to 62.8 % in Portugal. The average EU-27 old-age dependency ratio will be 52.0 % by 2050, after which it will start to decrease.

In 2018, in Slovenia, the life expectancy at birth was 81.5 years (78.5 years for men and 84.4 years for women) (Eurostat, 2020). In 2019, life expectancy at the age of 65 was 20.1 years; 21.8 for women and 18.1 for men.

The proportion of people aged over 65 in Slovenia is increasing and will continue to do so by 2050. The increase is fast: while the share of people aged 65+ amounted to 16.3 % in 2008, it was 19.8 % in 2019. The trend is predicted to continue. The number of potential dependants aged 65+ will increase from 107,800 to 172,500 by 2050. At the same time, the share of the eldest group will continue to increase as well: the share of people aged 75+ was 7.1 % in 2008, 9.1 % in 2019, and is predicted to reach 11.9 % by 2030 and 17.0 % by 2050. According to the latest data (2019), the share of potential dependants in the total population was 10.0 %. By 2030, their share is predicted to increase to 11.0 % and 12.4 % by 2050.

Of the older people aged 65+, 7.2 % receive residential care, 7.0 % receive home care, and 7.1 % receive cash benefits, which means that the total of 21.3 % receive LTC in any of these forms.

## 1.2 Governance and financial arrangements

So far, there has been no single, overarching legislative act specifically regulating LTC and no definition of LTC in national legislation. This means that, at present, services, which could be classified as LTC are provided through different social protection systems: the health care system, the social care system, the parental care system, pension system, educational system

[914] All data used in the text come from Section 5 'Background statistics' unless explicitly stated otherwise.
[915] Eurostat, *Databrowser*, https://ec.europa.eu/eurostat/databrowser/view/tps00198/default/table?lang=en (accessed 23 April 2020)
[916] EU-27 refers to the current 27 Member States of the European Union.

and disability care system with different entry points and different procedures concerning the assessment of entitlements to supplements to support LTC needs.[917]

Family is the primary provider of informal care for older people in Slovenia. If the cost of LTC exceeds the care recipient's ability to pay, their family (partner or grown-up children) is legally required to contribute (the rest), also following means testing.[918]

Total public LTC expenditure amounted to 1.0 % of GDP in 2019.

LTC health (measured as government and compulsory contributory financing schemes as a % of GDP) is predominant with 0.8 % of GDP in 2018. LTC social counts for 0.1 % for GDP in 2018 (Section 5 'Background statistics'). The resources for LTC health care are generated through compulsory healthcare insurance contributions and through pension and disability insurance contribution. They are collected by the Tax Office and transferred to the Health Insurance Institute of Slovenia (HIIS) and to the Pension and Disability Insurance Institute of Slovenia. Most of the LTC healthcare services offered to older people, either in institutional or home care, are 100 % covered by HIIS. Cash benefits are mainly paid from the Pension Institute and partly from the Ministry of Labor, Social Affaires and Equal Opportunities.

The share of public spending on LTC is mainly directed to residential care (53.5 %), followed by cash benefits (25.8 %) and home care (20.7 %).

Public resources for social services which could be classified as LTC are collected through taxes at the national and municipality level. They are used for subsidising LTC services (municipality level). Most of the expenditure on the social care function of LTC is private (paid by the people receiving care). It is used for the payment of accommodation and food in nursing homes and other forms of residential care, as well as household expenditure on home help. As much as 81.9 % of these expenses are covered from private sources, and the rest is subsidised by municipalities (Association of Social Institutions of Slovenia, 2019). Private LTC insurance in Slovenia does not exist.

## 1.3 Social protection provisions

Services, which could be classified as LTC services in Slovenia comprise of benefits in kind (health care and social care services in the form of residential care as well as community and home care) and cash benefits. There is no standard model of needs assessment. Eligibility is linked to individual services and decided by a team of experts (general practitioner, nurse, social worker) for residential care or by an individual expert (e.g. social worker) in the case of

[917] Nolte, E. et al., *Analysis of the health system in Slovenia: Purchasing and Payment Review − Final Report, 2015,* European Observatory on Health Systems and Policies, Ministry of Health, World Health Organisation, Ljubljana, 2015. http://www.mz.gov.si/fileadmin/mz.gov.si/pageuploads/Analiza/21012016/21012016_optimizing_service_delivery_ds5.pdf (accessed 28 March 2020)

[918] Decree on the Criteria for Defining Exemptions in the Payment of Social Assistance Services [Uredba o merilih za določanje oprostitev pri plačilih socialno varstvenih storitev], *Official Gazette of the Republic of Slovenia*, No 110/2004, with amendments, Ljubljana, http://www.pisrs.si/Pis.web/pregledPredpisa?id=URED3348 (accessed 20 March 2020)

home care. Similarly, cash benefits are granted upon application and approval by an expert team.[919,920]

**Residential care** covers basic care (housing, cleaning, washing, and meals) as well as social care and healthcare. For older people, it is organised in homes for older people (also as day care) and sheltered housing. The entitlement of the user to residential care is based on the Rules on Procedures Concerning the Exercising of the Right to Residential care.[921] Homes for older people are intended for those who are − as a result of old age (65+) or other reasons − not able to live independently and are in need of further help and care and are older than 18 years. Besides residential care, residential care covers day care in homes for older people. Residential care is also provided by sheltered housing that is intended for older people who cannot fully take care of themselves but can still live independently with the help of professional staff. Sheltered housing is usually located near homes for older people.[922]

**Services at home (including home care)** are organised through community nursing care, home help and a family assistant (carer). Community nursing care is organised as an independent service within the primary healthcare centres. It is intended for people who require nursing care due to illness, chronic disability or developmental disorder. It covers nursing care, such as wound care, injections, and taking samples for laboratory examination. Home care includes social care at home, such as basic domestic daily operations, household help, and the preservation of social contacts. People entitled to home help are those who live at home, but as a result of old age, illness, or disability require care assistance, and their relatives are not able to provide suitable help. Home help is carried out by different providers, such as centres for social work and public or private residential care institutions. Family assistant (carer) substitutes full-time residential care by providing care at home. A carer must have left employment with the intention of becoming a carer for a family member. Besides social security and healthcare insurance rights, the carer is entitled to a monthly payment for the loss of income. The carer must perform the following tasks: personal care, nursing care, social care, organisation of free time activities, and domestic help.

Cash benefits are regulated by various acts[923] and paid directly to the person in care (or the parent, in the case of children). For example, the attendance and assistance allowance is

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[919] Dominkuš, D., Zver, E., Trbanc, M., and Nagode, M., *Long-term care – the problem of sustainable financing. Slovenian reform of the long-term care system, Host country paper, Peer review on financing of long-term care*, Ljubljana, 2014. http://www.ec.europa.eu/social/BlobServlet?docId=13212 and langId=en (accessed 23 April 2020)

[920] Nagode M. Zver, E., Marn, S., Jacović, A., and Dominkuš, D., *Dolgotrajna oskrba: uporaba mednarodne kvalifikacije v Sloveniji* [Long-term care: use of international definitions in Slovenia], Institute of Macroeconomic Analysis and Development, Ljubljana, 2014. http://www.umar.gov.si/fileadmin/user_upload/publikacije/dz/2014/DZ_02_14p.pdf (accessed 23 April 2020)

[921] Rules on Procedures Concerning the Exercising of the Right to Residential care [Pravilnik o postopkih pri uveljavljanju pravic do institucionalnega varstva], *Official Gazette of the Republic of Slovenia*, No 38/2004, with revisions, Ljubljana, http://www.pisrs.si/Pis.web/pregledPredpisa?id=PRAV4776 (accessed 27 April 2020)

[922] Ministry of Labour, Family, Social Affairs and Equal Opportunities, *Varstvo starejših* [Older person care], Ljubljana, 2020. https://www.gov.si/podrocja/socialna-varnost/varstvo-starejsih/ (accessed 23 April 2020)

[923] Parental Protection and Family Benefits Act [Zakon o starševskem varstvu in družinskih prejemkih (ZSDP-1)], *Official Gazette of the Republic of Slovenia*, No 26/2014, Ljubljana. http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO6688 (accessed 9 April 2020); Pension and Disability Insurance Act [Zakon o pokojninskem in invalidskem zavarovanju (ZPIZ-2)], *Official Gazette of the Republic of Slovenia*, No 96/2012, Ljubljana. http://www.uradni-list.si/1/objava.jsp?urlid=201296 and stevilka=3693 (accessed 13 February 2018); Social Assistance Act [Zakon o socialnem varstvu], *Official Gazette of the Republic of Slovenia*, No 3/2007 (official consolidated text), Ljubljana.

regulated by six different acts; hence it can be in various forms, depending on the act on which it is based: the attendance allowance according to the pension and disability regulations, attendance allowance for the minimum income beneficiaries, assistance and aid allowance for people with severe disabilities, attendance allowance according to the regulations for war veterans, etc. There is no correlation between the level of need of the person in care and the amount granted. The amounts are set to different values depending on the status of the recipient. A person is entitled to only one cash benefit, even though based on different acts. The two most frequent cash benefits in LTC are the allowance for care and assistance by another person and the attendance and assistance allowance.

## 1.4 Supply of services

Residential care is, by tradition, well developed in Slovenia. In 2020, there are 102 homes for older people (59 public and 43 private). Residential care covered 4.5 % of the population aged 65+ 2019. Public homes have 13,206 places available for the care recipients, while private homes have 5361.[924] Also, 2496 places for people with special needs are available. Both the number of institutions and the number of residents have constantly been increasing since 1990. In 2017, 1012.4 beds per 100,000 inhabitants were available in nursing and residential facilities (Section 5 'Background statistics'). There were 2.3 LTC workers per 100 people aged 65+ in 2016, and 94 % of them were women.

As much as 6.1 % of people aged 65+ self-reported the use of home care services in 2014 (Section 5 'Background statistics'). The number of social workers providing home care has been fairly stable since 2010 and reached the total of 1007.3 in 2018. Almost all (98.8 %) of them were regularly employed. One social worker cared for 7.7 users in 2018. As much as 97.1 % of carers were women.[925]

The share of the population providing informal care was 10.7 % in 2016. Of them, 20.8 % provided more than 20 hours of care per week (Section 5 'Background statistics'). A more conservative estimate is based on the 2010 SHARE[926] data: around 48,000 informal carers

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http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO869; Social Assistance Benefits Act [Zakon o socialno varstvenih prejemkih (ZSVarPre)], *Official Gazette of the Republic of Slovenia*, No 61/2010, Ljubljana. http://pisrs.si/Pis.web/pregledPredpisa?id=ZAKO5609; Social Inclusion of Disabled Persons Act [Zakon o socialnem vključevanju invalidov (ZSVI)], *Official Gazette of the Republic of Slovenia*, No 30/2018, Ljubljana. http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO7808; War Disability Act [Zakon o vojnih invalidih (ZVojl)], *Official Gazette of the Republic of Slovenia*, No 63/1997, with amendments, Ljubljana. http://www.pisrs.si/Pis.web/pregledPredpisa?id=ZAKO961; War Veterans Act [Zakon o vojnih veteranih (ZVV)], *Official Gazette of the Republic of Slovenia*, No. 110/2003, Ljubljana. http://pisrs.si/Pis.web/pregledPredpisa?id=ZAKO3819; Exercise of Rights to Public Funds Act [Zakon o uveljavljanju pravic iz javnih sredstev], *Official Gazette of the Republic of Slovenia*, No 62/2010, Ljubljana. http://www.uradni-list.si/1/content?id=99290; Health Care and Health Insurance Act [Zakon o zdravstvenem varstvu in zdravstvenem zavarovanju], *Official Gazette of the Republic of Slovenia*, No 9/1992, No 72/2006 (official consolidated text), Ljubljana. http://www.uradni-list.si/1/objava.jsp?urlid=200672 and stevilka=3075. Links accessed 9 April 2020 unless stated otherwise.

[924] Association of Social Institutions of Slovenia, Splošno o domovih za starejše [General information on homes for elderly], Ljubljana, 2020. http://www.ssz-slo.si/splosno-o-domovih-in-posebnih-zavodih/ (accessed 27 March 2020)

[925] Kovač, N., Orehek, Š., Černič, M., Nagode, M., and Kobal Tomc, B., *Izvajanje pomoči na domu: Analiza stanja v letu 2018* [Implementation of home help: The 2018 situation analysis], Social Protection Institute of the Republic of Slovenia, Ljubljana, 2019. https://www.irssv.si/upload2/pnd/Analiza %20izvajanja %20PND %20za %20leto %202018.pdf (accessed 26 March 2020)

[926] Survey of Health, Ageing and Retirement in Europe (http://www.share-project.org/home0.html).

were offering help outside their household and 37,000 within their household.[927] They are mostly women.

In the last 15 years, a trend towards privatisation has been observed.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

The health services, which could be classified as LTC is financed through the compulsory health insurance system. Conversely, social services, which could be classified as LTC are partially subsidised by the state or the municipality (for certain social groups), while the rest is paid out of pocket. Out-of-pocket expenditure for LTC accounted for 26.6 % of the total expenditure for LTC and amounted to EUR 138.6 million. Out-of-pocket expenditures are costs paid by the recipients of care for social LTC services, such as housing, social care and meals. If the amount paid by the user (and/or another liable person)[928] does not cover the service costs, the difference is financed from the local community or the central government budget. Access to publicly subsidised LTC services is means-tested. Based on the Decree on the Criteria for Defining Exemptions in the Payment of Social Assistance Services (2004), the relevant local Centre for Social Work decides on the partial or complete exemption of the user from payment for services. The Decree on the Criteria for Defining Exemptions in the Payment of Social Assistance Services (2004) defines the social security threshold, set as the amount of money that must remain at the disposal of the user of the services after paying for them. Furthermore, it defines the ability to pay, which is defined as the maximum amount that the user is able to contribute towards LTC services. If the amount paid by the user (and/or another liable person) does not cover the service costs, the difference is covered by the local community or the central government budget. If the user of the LTC service, asking for the exemption from payment, is the owner of property, the issuing of the written order on an exemption from payment is subject to the prohibition to sell or mortgage that property for the local community to be able to reimburse the amount paid for the residential care from the user's legacy. If the user asks for an exemption from payment of home-care LTC services, the inhibition to sell or mortgage applies only to the property that is not the user's permanent residence (Decree on the Criteria for Defining Exemptions in the Payment of Social Assistance Services, 2004).

Residential care is occupied to its full capacity; the occupancy coefficient has been almost 100 % since 2009. The waiting lists are long; in April 2020, there were 12,849 people (or 3.11 % of all people age 65+) waiting for a place in a home for older people (Association of Social Institutions of Slovenia, 2020). This number is high, especially compared to the share

[927] Nagode, M., and Srakar, A., 'Neformalni oskrbovalci: kdo izvaja neformalno oskrbo, v kolikšnem obsegu in za koga' [Informal carers: who provides informal care, in what quantity and for whom], in Majcen, B., *Značilnosti starejšega prebivalstva v Sloveniji - prvi rezultati (Ageing in Slovenia - first results),* Institute for Economic Research (IER), Ljubljana, 2015, pp. 232-243. http://www.share-slovenija.si/files/documents/prvi_rezultati_slovenija/Publikacija_IER_23.pdf (accessed 6 April 2020)

[928] Liable people are a spouse, a long-term partner, or another person in the case of specific legal contracts.

of the population aged 65+ receiving care in an institution, which was 7.2 % in 2019. Nevertheless, it is worth noting that many people go on the waiting list, but do not decide to go to the institution when they are invited to. Municipalities vary in their ability to provide adequate community-based LTC services for older people; in particular, there are differences between urban and rural areas.[929] Available evidence suggests that rural areas especially frequently do not provide sufficient residential care and home care services, while urban areas tend to offer a wide range of services.[930] Affordability is getting worse for older people in residential care. There is a deficit between the average pension per day and payment for LTC per day which has been increasing since 2008.

The share of the population aged 65+ receiving care at home was 7.0 % in 2019. Also in home care, unmet needs were considerable. The share of households in need of LTC not using professional home care services for financial reasons was 27.4 %. In the same year, 6.7 % of households did not use professional homecare services because these were not available. Slovenia is one of the countries limiting the number of hours of home care to ensure that residential care is used when it is a cheaper option, which frees up resources to be used elsewhere in the LTC system.[931]

The cost of home help, paid by recipients of care, varies across municipalities and providers and ranges from EUR 0 (in the municipality of Odranci) to EUR 9.00 (in the municipality of Destrnik) per hour. The total amount spent on home help in 2018 was EUR 25.3 million, out of which municipalities financed EUR 18.3 million.

At the end of 2018, there were 7783 users and 82 providers of home help in Slovenia. Home help is available in 137 out of 211 municipalities every day in the morning and afternoon. In 48 municipalities, it is available only on weekdays in the morning. As concerns the potential unsatisfied needs, it has been evaluated that, at the end of 2018, 1090 people were waiting to receive home help. Due to various approaches to the organisation of social home care across municipalities, access to services varies greatly, especially regarding financial accessibility (Kovač et al., 2019).

## 2.2 Quality

In Slovenia, there is no national or general LTC quality framework in either healthcare or social part of the LTC services.

[929] Hlebec, V., Nagode, M., and Filipovič Hrast, M., *Kakovost socialne oskrbe na domu: vrednotenje, podatki in priporočila* [Quality of home social care: evaluation, data and recommendations], Faculty of Social Sciences, Ljubljana, 2014. https://www.fdv.uni-lj.si/docs/default-source/zalozba/pages-from-oskrba_out.pdf?sfvrsn=2 (accessed 17 May 2020)
[930] Association of Social Institutions of Slovenia, Poudarki iz analiz področja institucionalnega varstva starejših in odraslih s posebnimi potrebami [Emphases from the analyses of residential care for older people and adults with special needs], Ljubljana, 2019. http://www.ssz-slo.si/wp-content/uploads/2018_POUDARKI-IZ-ANALIZ-2018.pdf (accessed 27 March 2020)
[931] Muir T., 'Measuring social protection for long-term care', *OECD Health Working Papers* No 93, OECD Publishing, Paris, 2017, https://www.oecd-ilibrary.org/docserver/a411500a-en.pdf?expires=1590771781 and id=id and accname=guest and checksum=A5604D48A49A8BD18ADEB4ADCE139CB7 (accessed 29 May 2020)

Quality assurance is limited to the fulfilment of minimal technical specifications for social services.[932,933]These specifications are laid down in law. Technical specifications refer to the location, land, premises, entrance, telecommunications, equipment, and space of the premises. Technical requirements must be fulfilled to obtain permission to open an LTC facility.

Besides technical requirements, the Rules on the Standards and Norms for Social Services[934] define standards and norms for initial social help (estimation of social needs, providing the information), personal care, home help, residential care and management, safety, and employment under special circumstances (for people with disabilities).

The Rules on Concessions in the Field of Social Assistance [935] define the following requirements for a legal entity to obtain a concession: registration of the entity in Slovenia; fulfilment of all technical conditions, standards and norms concerning staff; a detailed programme for providing services; financial solvency; and quality provision of services. The definition of 'quality provision of services' is not elaborated further.

In the health care sector, the framework of quality indicators is included in the general agreement with the providers of care. Selected and agreed indicators need to be reported quarterly to the Ministry of Health using Lime survey.[936] Some examples are Share of Day Surgery, 30-day hospital mortality due to an acute heart attack or stroke, Share of non-provided services due to the absence of the patient, and Use of e-Health Services. There is also a broader list of 73 quality indicators.[937] However, there are no indicators that are specific to health care services in LTC because, as already mentioned, there is no definition of LTC and no uniform LTC system.

In general, all providers of social care are monitored by the Social Inspectorate, which is a body within the Ministry for Labour, Family, Social Affairs and Equal Opportunities.[938] The inspections are based on risk assessments or an external request by users. In 2018, there were

[932] Rules Concerning Minimal Technical Conditions for Providing Residential care Services for Elderly, Home Help Services and Social Service [Pravilnik o minimalnih tehničnih pogojih za izvajanje storitev institucionalnega varstva starejših oseb, pomoči na domu in socialnega servisa], *Official Gazette of the Republic of Slovenia*, Nos 54/1992 and 42/1994, Ljubljana. https://www.uradni-list.si/glasilo-uradni-list-rs/vsebina/1999-01-0284?sop=1999-01-0284 (accessed 25 March 2020)

[933] Rules Concerning Technical Conditions for Providing Social Service of Guidance, Care and Employment under Special Conditions and for Providing Residential care to Users of Such Service [Pravilnik o tehničnih pogojih za izvajanje socialno varstvene storitve vodenje in varstvo ter zaposlitev pod posebnimi pogoji ter za izvajanje institucionalega varstva uporabnikov te storitve], *Official Gazette of the Republic of Slovenia*, Nos 101/2000 and 67/2006, Ljubljana. http://www.pisrs.si/Pis.web/pregledPredpisa?id=PRAV3637 (accessed 26 March 2020)

[934] Rules on the Standards and Norms for Social Services [Pravilnik o standardih in normativih socialnovarstvenih storitev], *Official Gazette of the Republic of Slovenia*, No 42/2010, with amendments). Ljubljana. http://www.pisrs.si/Pis.web/pregledPredpisa?id=PRAV10060 (accessed 22 March 2020)

[935] Rules on Concessions in the Field of Social Assistance [Pravilnik o koncesijah na področju socialnega varstva], *Official Gazette of the Republic of Slovenia*, Nos 72/2004, 113/2008 and 45/2011), Ljubljana. http://www.pisrs.si/Pis.web/pregledPredpisa?id=PRAV5639 (accessed 27 March 2020)

[936] Ministry of Health of the Republic of Slovenia, '*Sporočanje podatkov o kazalnikih kakovosti v zdravstvu – spletna anketa*' [Reporting data on quality indicators in health care – web survey], Ljubljana, 2018. https://www.gov.si/teme/kakovost-zdravstvenega-varstva/ (accessed 26 March 2020)

[937] Poldrugovac, M., and Simčič, B., *Priročnik o kazalnikih kakovosti* [Manual on the quality indicators], Ministry of Health of the Republic of Slovenia, Ljubljana, 2010. https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Dostopnost-in-varnost-zdravstvenega-varstva/Kakovost-zdravstvenega-varstva/Navodila/11cc816388/Prirocnik-o-kazalnikih-kakovosti.pdf (accessed 25 March 2020)

[938] Rules on Carrying out Inspections in the Field of Social Assistance Services [Pravilnik o izvajanju inšpekcijskega nadzora na področju socialnega varstva], *Official Gazette of the Republic of Slovenia*, Nos 74/2004 and 39/2016), Ljubljana. http://www.pisrs.si/Pis.web/pregledPredpisa?id=PRAV5642 (accessed 6 April 2020)

29 inspections in the residential care for older people, 15 in institutions for LTC of people with disabilities, 24 inspections of home care, and three inspections of social services.[939] The results of inspections are publicly available. Between 2012 and 2017, there were 24 infringement decisions issued by the Social Inspectorate for homes for older people. Half of them were related to the lack of personnel in homes for older people, nine to inappropriate treatment of the recipients of care (like non-respecting of spatial norms and charging incorrectly for care provision).[940]

A regular framework for monitoring informal care is not in place. In cases where maltreatment is reported, the competent Centre for Social Work intervenes and provides assistance.

## 2.3 Employment (workforce and informal carers)

In 2016, there were 2.3 LTC workers per 100 individuals aged 65+. Out of them, 94 % were women (Section 5 'Background statistics'). This number is very low compared to other EU-27 countries (EU-27 average is 3.8), which indicates issues regarding availability and retention of personnel in the LTC. The first reason for the low availability of workers in LTC is the low norms regarding the number of workers per recipient of care (one per 1.74 recipients) (Association of Social Institutions of Slovenia, 2019). The Slovenian norms are obsolete and were planned to be addressed by a new Act on LTC.[941] Low norms on staffing mean that homes for older people cannot employ more people paid out of public sources, as this would mean an additional financial obligation for which they do not get payment from the public funds. The second issue is that the workers needed in LTC are not available. Due to low salaries[942] as well as the heavy and demanding work, young people do not study nursing care, and educated carers do not apply for jobs in LTC in Slovenia. Many educated workers commute daily across the border to work for higher pay in Austria or Italy.[943] There is a lack of almost all types of workers, especially workers for basic and social care services in homes for older people. These institutions thus have to use alternative solutions to be able to take care of their users, such as employing unqualified staff and providing them with training, and engaging students to do work experience in homes for older people.

[939] MLFSAEO, *Inšpekcijski nadzori v letu 2018 [Inspections in 2018*], Ministry of Labour, Family, Social Affairs and Equal Opportunities, Ljubljana, 2019. https://www.gov.si/assets/organi-v-sestavi/IRSD/Socialne-zadeve/a1847253f2/Vsebinsko-porocilo-za-leto-2018.pdf (accessed 24 March 2020)

[940] Pirnat T., 'Kateri domovi za starejše so kršili socialnovarsteno zakonodajo*'* [Which homes for older people did not act in line with social care legislation], *Under the Line: Medium for Independent Journalism*, Ljubljana, 2018. https://podcrto.si/kateri-domovi-za-starejse-so-krsili-socialnovarstveno-zakonodajo/ (accessed 24 April 2020)

[941] Draft Act on Long-term Care and Compulsory Insurance for Long-term Care [Zakon o dolgotrajni oskrbi in obveznem zavarovanju za dolgotrajno oskrbo: osnutek], Ministry of Health of the Republic of Slovenia, Ljubljana, 2017. https://www.irssv.si/upload2/20102017_o_Z_o_dolg__oskrbi_JR.pdf (accessed 30 March 2020)

[942] The average gross salary per employee in LTC was EUR 1447.63 in December 2019, or 78 % of the average gross average wage in Slovenia in the same month. However, the lowest paid carers earned a minimum wage, which amounted to EUR 886.63 (Statistical Office of the Republic of Slovenia, 2020)

[943] Pirnat T., 'Domovi za starejše: premalo kadra za zdravstveno in za socialno oskrbo*'* [Homes for Older People: Not enough workers for health and social care], *Under the Line: Medium for Independent Journalism*, Ljubljana, 2018. https://podcrto.si/domovi-za-starejse-premalo-kadra-za-zdravstveno-in-za-socialno-oskrbo/ (accessed 24 April 2020)

Research[944] estimated that, in 2015, formal LTC was carried out by 11,514 employees or 3.1 employees per 100 people aged 65+.[945] As not all of these employees were fully employed, the actual numbers are slightly lower and amount to 2.7 employees per 100 people aged 65+. The estimation is that 70 % are employed in residential care and 30 % in home care. Most of the employees were nurses-carers (22.4 %), followed by high-school educated nurses (17.7 %), family helpers and other recipients of subsidies[946] (14.7 %), university-educated nurses (13.4 %) and other carers (20 %). Out of all employees, 58.7 % provided health care, and the rest provided social care (Smolej Jež et al., 2016). In 2018, there were 12,125 employees in residential care, with 1.74 users per employee on average in homes for older people (1.80 in private and 1.71 in public homes for older people) and 1.48 in special care homes (Association of Social Institutions of Slovenia, 2019). The burden per employee has been decreasing since 2015. Out of all employees in residential care, 6017 were employed in social care, 5436 in health care, and 673 in general business.

The number of social carers providing home care has been fairly stable since 2010 and reached 1007.3 in total in 2018. Out of them, 98.8 % were regularly employed, either full- or part-time (61.8 % in 2010). As many as 97.1 % of carers were women. (Kovač et al., 2019).

It was estimated using the 2010 SHARE data that there were around 48,000 informal carers offering help outside their household and 37,000 offering help within their household (Nagode and Srakar, 2015). Using the same data, it was found that informal carers prevailed in the care for older people, especially in carrying out instrumental activities of daily life (Hlebec et al., 2014). There were significantly more women (59.2 %) than men, and most (57.6 %) carers were between 50 and 64 years of age.

A recent study[947] showed that 9.6 % of the population are informal carers. On average, they spend 28.8 hours a week caring mostly for relatives or neighbours. Around half (51 %) of them are women, and 70.8 % are aged between 35 and 64 years old. EQ-5D-5L scores, CarerQol-7D scores and CarerQol-VAS that measure the health-related quality of life of informal care providers were significantly lower than for respondents who do not provide informal care. As much as 84 % of caregivers felt some or a lot of fulfilment in providing care. The problems associated with combining care tasks with daily activities, however, seem very serious. To significantly improve the reconciliation of LTC and work, more flexible employment arrangements are needed for employees with LTC obligations. There is also a clear need for training and more support to informal carers, like respite services, an allowance

[944] Smolej Jež, S., Nagode, M., Jacović, A., and Dominkuš, D., *Analiza kadra v dolgotrajni oskrbi* [Analysis of the human resources in long-term care], Social Protection Institute of the Republic of Slovenia, Ljubljana, 2016. https://www.irssv.si/upload2/analiza_kadra_v_do.pdf (accessed 27 March 2020)

[945] For the first time, LTC occupational profiles from the public sector job registry plus other occupational profiles that provide formal LTC outside the public sector were included in the analysis at the national level, making the number of employees higher than the internationally reported one.

[946] Other recipients of subsidies are parents who stop working (fully or partially) to take care of a child with mental disabilities.

[947] Baji, P., Golicki, D., Prevolnik Rupel, V., Brouwer, WBF., Zrubka, Z., László, G., and Péntek, M., 'The burden of informal caregiving in Hungary, Poland and Slovenia: results from national representative surveys', *European Journal of Health Economics,* Vol. 20 (Suppl 1), 2019, pp. 5–16. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6544749/ (accessed 30 March 2020)

compensating for (a part of) the cost of respite services, social security insurance of informal carers, etc.[948]

## 2.4 Financial sustainability

In the future, LTC spending as a percentage of GDP is expected to increase further. The Ageing Working Group (AWG) reference scenario of the 2021 Ageing Report[949] sets LTC spending to 1.0 % of GDP in 2019 and with an increase by 2050 to 1.9 % in the reference scenario and 3.3 % in the risk scenario (see Section 5). It is predicted that public spending on residential care will increase slowly, reaching 55.0 % in 2050 (53.5 % in 2019). Simultaneously, public spending on home care will increase as well, reaching 28.1 % in 2050 (20.7 % in 2019). Cash benefits are predicted to drop sharply, from 25.8 % in 2019 to 16.9 % in 2050 (Section 5 'Background statistics', Table A1).

Due to an unsustainable system of financing LTC, Slovenia's goal − set out in the latest submitted (but not passed) Act on LTC (Draft Act on Long-term Care and Compulsory Insurance for Long-term Care, 2017) − is to enhance home care and decrease residential care, as well as prioritise a unified entrance criteria for the LTC system, and efficient and high-quality services provision.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

The other age groups in need of LTC can use residential care for people with special needs. There are ten such homes in Slovenia, with 1548 places. There are also five Centres for Training, Work and Care for people up to 26 years of age. These centres provide residential care with social care, special education and health care. If the person fulfils the criteria for enrolment into the programme, they have the right to be accepted. Adult people with lessened abilities can find employment through Centres for Care and Work. However, the quality of care for adults is not at the same level as for younger people. The process of deinstitutionalisation has started recently. Initiatives to provide care in smaller communities are still in the pilot phase, financed by the government and EU funds. The choices are hence still very limited for parents and recipients of care.[950]

# 3 REFORM OBJECTIVES AND TRENDS

In July 2019, the Council of the European Union recommended Slovenia to adopt and implement an LTC reform that ensures quality, accessibility and long-term fiscal

[948] Stropnik, N., and Prevolnik Rupel, V., *ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives, Slovenia*, European Social Policy Network (ESPN), European Commission, Brussels, 2016. http://ec.europa.eu/social/keyDocuments.jsp?pager.offset=0 and langId=en and mode=advancedSubmit and year=0 and country=0 and type=0 and advSearchKey=ESPNwlb (accessed 30 March 2020)

[949] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

[950] Pelicon M., 'Postopek sprejema v CUDV' [The procedure of entering Centres for Training, Work and Care], *Vita*, 2016, https://www.revija-vita.com/vita/86/Postopek_sprejema_v_CUDV (accessed 31 March 2020)

sustainability.[951] A very diverse, multi-activity pilot project 'Implementation of pilot operations' is currently underway as the bases for the preparation of the new draft Act on LTC.

The specific objectives of pilot activities, launched in 2018 by the Ministry of Health, are to test the following services and procedures:

1. Eligibility assessment – testing at the point of entry (assessment tools and procedures, entry threshold, preparation of personal plans, monitoring the implementation plan).
2. New services and integrated care – testing by the LTC provider (integrated LTC team consisting of care unit and unit for maintaining autonomy, combinations of formal and informal care, new services including e-care and the implementation plan, quality monitoring).
3. Coordinated activities (in integrated LTC teams, between different service providers of social and health care, overarching projects at the local and national level).

The LTC system was heavily hit by the COVID-19 epidemic, resulting in an employee strike against difficult conditions in 70 homes for older people on 24 April 2020.[952] In long-term care, the homes for older people were severely affected by the COVID-19 pandemic. By the end of 2020, the number of confirmed cases of SARS-CoV-2 among the recipients in institutions reached 10,800, which is almost half of all LTC recipients in institutions. 1,781 elderly in institutions died which was 57% of all deaths in Slovenia.[953]

In substance, no LTC reform has been implemented in Slovenia until now (between 1 January 2017 and 1 May 2021), however new draft Act on LTC was in public debate in October and November 2020. It is very positive to see that current preparations in the form of pilot projects are ongoing and promise to provide a solid basis for the new draft Act on LTC in all areas (access, affordability, quality, employment, and financing).

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

Due to different legal bases, different entry mechanisms and different assessment scales, beneficiaries with comparable needs do not necessarily have comparable rights and comparable support. Both private and public expenditure in the field of LTC are increasing, which reduces the access to, and availability of, services to individuals from disadvantaged socio-economic backgrounds. As the country specific recommendations since 2014 state, rising age-related expenditure on pensions, health care and LTC is putting pressure on public finances in the long-term. In this context, the recommendations of the European Semester have included calls for LTC reform.

The key objectives in implementing a new LTC system are to:

[951] Recommendation for a Council recommendation on the 2019 National Reform Programme of Slovenia and delivering a Council opinion on the 2019 Stability Programme of Slovenia, Council of the European Union, 2019. http://data.consilium.europa.eu/doc/document/ST-10177-2019-INIT/en/pdf (accessed 29 May 2020)

[952] C., G., and R., B., *V raziskavi o razširjenosti novega koronavirusa odvzeli vse vzorce* [All samples taken in the research on the prevalence of new coronavirus], RTV SLO MMC, Ljubljana, 2 June 2020. https://www.rtvslo.si/zdravje/novi-koronavirus/v-raziskavi-o-razsirjenosti-novega-koronavirusa-odvzeli-vse-vzorce/522499 (accessed 2 June 2020)
National Institute of Public Helath - NIJZ (2021) https://www.nijz.si/sl/dnevno-spremljanje-okuzb-s-sars-cov-2-covid-19

- unify the legal bases governing rights in the field of LTC;
- explain exactly what LTC is – establish a definition;
- define the scope of rights and the set of LTC services;
- establish a standardised needs assessment for entering the LTC system;
- enable insured person who want to remain at home for as long as possible to have access to integrated services in the community;
- to place an individual at the centre of the LTC system, with the right to choose the manner and form of LTC. In accordance with the principle of accessibility to LTC services and the principle of active participation, the insured person will have the opportunity to freely choose services, create a plan for the implementation and performance of services in the corresponding category;
- to manage the growing private funding of individuals, which increases the risk of poverty, especially for older people with envisaged higher funding from public sources;
- improve the planning, management and quality assurance, safety and efficiency of the implementation of LTC as a public service. One of the main objectives of LTC reform is to improve the quality and security of LTC. In order to improve the quality and safety of the provision of LTC, the draft law significantly strengthens the requirements on formal provision of services. Service providers must among other requirements provide appropriate technical conditions for the performance of activities and manage any conflicts of interest that would arise due to financial, personal or business relations between employees in LTC and the user;
- establish effective, integrated public supervision over the LTC system with a new supervisor.

In addition, it is planned to support the caregiver of a family member (as a special form of formal care) with the following rights in accordance with the proposed act:

- partial payment for lost income;
- inclusion in compulsory social insurance;
- planned absence and
- training and professional advice.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 2.0 | 2.1 | 2.1 | 2.0 |
| Old-age dependency ratio, 2019 | | 23.3 | 30.5 | 39.2 | 54.9 |
| Population 65+ (in millions), 2019 | Total | 0.3 | 0.4 | 0.5 | 0.6 |
| | Women | 0.2 | 0.2 | 0.3 | 0.3 |
| | Men | 0.1 | 0.2 | 0.2 | 0.3 |
| Share of 65+ in population (%), 2019 | | 16.3 | 19.8 | 24.4 | 30.7 |
| Share of 75+ in population (%), 2019 | | 7.1 | 9.1 | 11.9 | 17.0 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.2* | 20.1 | | |
| | Women | 21.0* | 21.8 | 23.0 | 25.0 |
| | Men | 16.8* | 18.1 | 19.2 | 21.3 |
| Healthy life years at the age of 65, 2018 | Total | 6.9* | 7.4 | | |
| | Women | 7.2* | 7.4 | | |
| | Men | 6.6* | 7.5 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 209.0 | 232.0 | 253.2 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 107.8 | 133.8 | 172.5 |
| | Women | | 69.8 | 83.2 | 104.1 |
| | Men | | 38.0 | 50.5 | 68.4 |
| Share of potential dependants in total population (%), 2019 | | | 10.0 | 11.0 | 12.4 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 25.7 | 25.8 | 27.5 |
| Share of population 65+ in need of LTC** (%), 2019* | | 32.6 | 29.2 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 7.2 | 7.3 | 8.8 |
| Share of population 65+ receiving care at home (%), 2019 | | | 7.0 | 7.2 | 8.6 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 7.1 | 7.3 | 8.8 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 54.9 | 56.0 | 63.3 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 27.6 | 28.3 | 31.9 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 38.7 | 38.8 | | |
| | Women | 39.1 | 39.5 | | |
| | Men | 37.7 | 37.5 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 8.3 | 6.1 | | |
| | Women | 10.4 | 7.0 | | |
| | Men | 5.3 | 4.8 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 27.4 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 6.7 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 992.4 | 1,012.4 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 1.9 | 2.3 | | |
| | % Women | | 94.0 | | |
| Share of population providing informal care (%), 2016 | Total | | 10.7 | | |
| | Women | | 12.3 | | |
| | Men | | 9.0 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 20.8 | | |
| | Women | | 22.9 | | |
| | Men | | 17.8 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.4 | 1.0 | 1.2 | 1.9 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.4 | 1.0 | 1.6 | 3.3 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 43.1 | 53.5 | 52.5 | 55.0 |
| Public spending on home care as % of total LTC public spending, 2019 | 21.4 | 20.7 | 28.7 | 28.1 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 35.5 | 25.8 | 18.8 | 16.9 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | - | 0.8 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | 0.1 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | - | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | 0.3 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# SLOVAKIA

***Highlights***

- *The share of people aged 65+ will grow by 13.4 percentage points (p.p.) by 2050, resulting in the increase of the share of potentially dependent people aged 65 + by 4.2 p.p.*
- *LTC in Slovakia relies heavily on informal care. As regards formal care, provision of residential care prevails. However, the number of the LTC workers is among the lowest in the EU.*
- *Quality of social services, including LTC, has become an object of systematic action by the government. The process of regular assessments of quality in social services was recently launched.*
- *Several reforms have been implemented recently, including financing of social services, introducing new measures for relatives and increasing the support for caregivers.*
- *Lack of coordination between the social and health care sector, low capacities of home care/residential and nursing care services, and the low level of spending on LTC remain important challenges for future action.*

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends[954]

The proportion of people aged 65 years old or more is projected to expand from 16.0 % in 2019 to 20.9 % in 2030, representing an increase of 4.9 p.p. The proportion of people aged 75 years old or more will increase by 3.4 p.p. to reach 9.5 % in 2030. The old-age dependency ratio is projected to increase from 23.5 % to 32.6 % over the period.

Between 2019 and 2050, the proportion of people aged 65+ will increase by 13.4 p.p., reaching 29.4 % in 2050. The relative importance of those aged 75+ is expected to grow at a slower pace. The proportion of people aged 75 years old or more will increase by 8.5 p.p., accounting for 14.6 % of the population in 2050. Projections suggest that the old-age dependency ratio will continue to climb and will more than double in the period 2019-2050: the ratio is projected to reach 51.4 % by 2050.

As a result, the number of potential dependants will expand significantly: it will grow by 17.3 % between 2019 and 2030, and by 37.9 % in the period 2016-2050. The share of potential dependants in the total population, accounting for 9.0 % in 2019, will reach 10.6 %

[954] All data used in the text come from Section 5 'Background statistics' unless explicitly stated otherwise.

in 2030 and 13.2 % in 2050 respectively. As a result, the need for accessible and high quality LTC services becomes an increasingly urgent issue.

Slovakia belongs to the EU-27[955] countries with a significant gender imbalance for very old people. It is most apparent among people aged 85 years old or more. In 2018, there were more than 2.5 women aged 85+ for every man in the same age group, representing the 7th highest ratio among the EU-27 countries. A large gap was also recorded for people aged 75-84 years: there were approximately 1.8 women per man in this age range, which was the 5th highest ratio in the EU-27 (Eurostat, 2019: 17)[956].

## 1.2 Governance and financial arrangements

Responsibility for long-term care (LTC) in Slovakia is formally divided between the Ministry of Labour, Social Affairs and Family (hereinafter MLSAF) and the Ministry of Health.[957] Under the auspices of the Ministry of Health, various interventions are provided based on public health insurance, including the use of geriatric clinics, medical and nursing residential facilities for the long-term ill, nursing care homes, and nursing home care agencies. Provision of health LTC is funded from health insurance. The MLSAF is responsible for social services (benefits in kind) and cash benefits. Cash benefits are paid either to the caregiver or the care recipient. They are funded from general taxation (applied at national level). Social services are provided mainly by self-governing local and regional authorities and financed from their budgets, clients' payments, and financial contributions from the MLSAF. Funding from the self-governing regions represents the most important source of social services financing.[958] Fees for LTC services (and social services in general) are set by public providers (municipalities, self-governing regions) and non-public providers, taking into account eligible costs and revenues from financial subsidies that were provided in previous year.

The out-of-pocket payments differ according to the type of LTC service. The out-of-pocket payments of home care are well below 50 % of the median income among older people. In the case of residential care, they represent a higher share of income (from 40 % to 65 %, depending on the level of the need).[959] There is no private insurance to cover these costs.

Although the formal care sector is relatively more important, informal carers represent a key element of the LTC services in Slovakia because it compensates for low capacities of formal LTC services. According to an official government report[960], informal carers are not adequately supported and financially remunerated.

[955] EU-27 refers to the current 27 Member States of the European Union.
[956] Eurostat, *Ageing Europe: looking at the lives of older people in the EU,* Publications Office of the European Union, Luxembourg, 2019.
[957] Unlike some EU countries, there is no legal obligation for children to care for their parents. Family members are expected to contribute to fees for LTC services.
[958] Ministry of Finance, *Review of spending on social policy and labour market*, Value for Money Unit, 2017.
[959] OECD, *Measuring social protection for long-term care in old-age*, OECD Publishing, Paris, 2019, page 52-53.
[960] Ministry of Finance, *Review of spending on healthcare sector*, Value for Money Unit, 2019.

## 1.3 Social protection provisions

Social protection provisions include social benefits for both caregivers and care recipients (people in need of assistance), as well as the eligibility conditions and regulation of the LTC services cost-sharing.

**Financial benefit for caregivers**

People who care for long-term dependent relatives can claim attendance service benefit (*príspevok na opatrovanie*). The condition is that they care for a person with disabilities who is aged six years old and over who − according to an official assessment − relies on care. Although the benefit is intended for the relative of a dependent person (person in need), it can be also paid to another person if they live with the dependent person (i.e. they have a common address of residence). Health and social insurance contributions for nursing allowance recipients are paid by the state.

Attendance service benefit is paid directly to caregivers in the form of a social transfer (paid by the office for labour, social affairs and family). Its level depends on several factors, including the number of care recipients, whether the caregiver receives statutory pension benefit or not (old-age pension, early old-age pension, invalidity pension), and use of social service facilities.[961] The benefit is increased by EUR 100 per month where a person cares for one or more children with severe disabilities or they have no earnings from work and, at the same time, do not receive any statutory pension benefit.

Attendance service benefit is means-tested according to the care recipient's income. This income may come from disability benefits and various other financial compensations that are offered to people with a severe disability. If someone cares for a person with severe disabilities who has an income above a certain threshold (twice the subsistence minimum for an adult), the level of the benefit is reduced. For carers of children with severe disabilities the threshold is higher (three times the subsistence minimum for an adult). Income-testing is not applied to care recipients receiving various types of pensions.

Provision of LTC may be combined with paid work, on condition that earnings from work do not exceed twice the subsistence minimum for an adult person. The benefit is also paid to caregivers who increase their qualifications by an external form of study, on condition that they ensure care for care recipients.[962]

Attendance service benefit cannot be paid if the care recipient (dependent person) receives the personal assistance allowance.[963] Further, it cannot be combined with the provision of (formal) home care exceeding eight hours per month, or with weekly or yearly residential care services.

[961] If the caregiver cares for one person with severe disabilities and they do not receive any statutory pension benefit, the benefit equals EUR 476.74. If the caregiver cares for one person with severe disabilites and they do not receive any statutory pension benefit, it equals EUR 238.37. These amounts were set in June 2020 – they represent an increase from the previous amount by EUR 46 in the first case and EUR 23 in the second case.
[962] The Act on Direct Payments for Severe Disability Compensation contains a caution, however, that the allowance is paid only for the days when long-term care is provided.
[963] The personal assistance allowance is provided to a dependent person on the condition that their relatives do not apply for the nursing allowance.

**Financial benefits for care recipients (dependent persons)**

There are several social benefits for people with disabilities. Almost all of them provide financial resources for the purchase of various aids necessary for people with disabilities (or for their modification, repair and training in use of the aid). We focus on the benefit that is aimed at supporting long-term care: personal assistance allowance (*príspevok na osobnú asistenciu*).

People with severe disabilities who are dependent on personal assistance are entitled to personal assistance allowance. Dependence on personal assistance is defined according to a list of activities of daily living and instrumental activities of daily living which require the assistance of other people. Personal assistants provide services on the basis of a contract (with the person with disabilities or a personal assistance agency). Provision of personal assistance is subject to a maximum of 7300 hours of personal assistance per year. One personal assistant can provide personal assistance for 10 hours per day.[964] Family members can deliver personal assistance for a maximum of four hours per day (and can only help with selected daily activities of the person with disabilities). The total amount of the allowance depends on the extent of activities provided by the assistant). Unlike the nursing allowance, the personal assistance allowance is subject to taxation (taxes are paid by the personal assistant). The old-age pension contributions of a personal assistant are paid by the state on condition that the personal assistant: provides services for at least 140 hours per month; has permanent residence in the Slovak Republic; is not covered by an old-age pension scheme for other reasons (as an employee, or through self-employment); is not of pensionable age; and does not receive an early old-age pension or invalidity pension.

**Eligibility conditions for LTC services and regulation of cost-sharing**

The provision of social services is contingent upon satisfying some conditions. A social and health assessment of the applicant's personal situation is the basis for any intervention in the field of LTC. It determines the degree of dependence and thus the extent of need for assistance.[965] Based on the decision of dependence on social service, a social care provider gives or ensures provision of social services, taking into account the waiting list.

Eligibility criteria for residential LTC facilities vary. Each type of residential LTC facility has its own eligibility criteria which takes into account age, degree of dependence, and other factors.

While provision of financial benefits relies on an assessment of the person's income (both the level of income and its sources are taken into account), social services are not income-tested.

[964] The limit doesn't apply if personal assistance is provided to a person with disabilities who is not in a permanent or temporary care residence.

[965]The health assessment, carried out by a health worker contracted by the municipality or self-governing region, focuses on the health status of the client and changes in it. The degree of dependence on assistance is identified according to a list of daily activities that require the help of other people. The social assessment, carried out by a social worker contracted by the municipality or self-governing region, focuses on: evaluating individual predispositions (ability and willingness to solve the unfavourable situation); family background (ability to help the dependent person and the extent of this help); and the context, which is important for social inclusion (for example, housing conditions or access to public services). The health and social assessments result in a final document on a person's dependence on social services, which contains information on: the degree of dependence; the list of daily activities requiring assistance (ADLs and IADLs); the number of required hours of care; the recommended type of social service, and the timing of the next health and social (re)assessment.

On the other hand, care recipients pay some fees that cover a (limited) part of social services costs. Fees for long-term care services are defined by public providers (municipalities, self-governing regions) and non-public providers. The Act on Social Services (§ 73) defines a minimum amount of income that must remain at a care recipient's disposal after deducting fees for services. For example, after paying charges for home care services, a recipient's income must be equal to at least 1.65 times the subsistence minimum (for an adult person). After paying fees for residential care provided for a whole year, a recipient's income must not be less than 25 % of the subsistence minimum. The income considered to determine the level of cost sharing excludes one-off state social benefits, child benefit, tax bonuses, scholarships etc. Assets are not taken into account if below a certain value.

## 1.4 Supply of services

Long-term care consists of four forms: formal care in the form of residential care, semi-residential care or home-care; and informal care.

Residential and semi residential care services are offered by various facilities which are aimed at various groups.[966] Home care services are provided by professional workers who work for public or private providers. Informal care is provided by family members, who can claim the care allowance. All these forms of services include social and health services.

Social services provided in social service facilities, consisting of residential and semi-residential services, represent the most frequent form of long-term care. In 2018, there were 51,476 places in social service facilities.[967] 92 % of the places were provided by the facilities which focused on services for 'people in need of assistance of another person'[968] (i.e. long-term care services). A majority of clients were older people aged 63 years or more (73 %) and people with the highest degree of dependence (68 %). Residential services represented the majority of long-term care provided in social service facilities (approximately 85 %).

Home care services for care recipients are delivered by public and private providers. Publicly run services are more common. In 2018, home care services were provided by 5747 municipal workers to 13,187 people, representing 82 % of all home care recipients. In the private sector, home care services were delivered to 2807 care recipients, relying on 2778 care workers.

As regards residential services in the health care sector, there were nine nursing care homes with 194 places and ten hospices providing 188 places in 2018.[969] Semi-residential services were provided by 128 day care centres with 1593 daily places and 22 mobile hospices. There were 157 providers of home nursing care agencies that provided long-term health care at home.

Information on informal carers is provided in Section 2.3.

[966] Including residential and semi-residential social care facilities (care homes for seniors, social service care homes, specialized care facilities, nursing care facilities, supported living accommodation, day care centres, rehabilitation centres) and health care facilities (hospices, nursing service homes, hospital wards, mobile hospices). For more information, see Ministry of Finance, *Review of spending on healthcare sector*, Value for Money Unit, 2019.
[967] Data in this section come from the *Report on the social situation of the population of the Slovak Republic in 2018*, published by the Ministry of Labour, Social Affairs and Family (2019).
[968] The term enclosed in double quotation marks represents an official expression used in the Slovak social policy.
[969] http://www.nczisk.sk/en/Pages/default.aspx. Data on hospital wards for long-term care are not available.

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

On average, the total costs of receiving LTC services (both home care and residential care) are approximately equal to the median disposable income for individuals of retirement age or older who have severe needs[970]. The vast majority of other OECD countries have significantly larger costs. The role of public policy in reducing LTC costs depends on the form of service and severity of needs. With home care, public policy helps, in particular, older people with moderate and severe needs. Approximately 60% of older people would be at risk of poverty after paying out-of-pocket costs of home care for moderate needs. Without social protection, 80 % of older people would face income poverty after paying out-of-pocket costs of home care for severe needs. Other OECD countries have a more significant impact of public policies (ibid). It is due to the lower costs of LTC services in Slovakia compared to in other countries and a lower incidence of income poverty among older persons.

On the other hand, when looking at residential care (for severe needs), public policy in Slovakia, like in many other countries, guarantees that any older person can afford it without being at risk of poverty.

However, the statistics on the impact of public policies hide the fact that there are significant differences between public and private LTC providers. The LTC costs in private facilities are much higher than those in the public sector, which have limited capacities and long waiting periods. Furthermore, there is evidence from media and public discourse that LTC costs in the public sector may also cause financial difficulties for care recipients and their families.[971]

With regards to informal carers, they can claim for attendance service benefit (see Section 1.3). As it is paid only to caregivers who care for people with severe disability, it does not cover those who care for other people depending on assistance. This is the case in particular for people who provide long-term care for their relatives without an official assessment of their degree of dependency. According to the spending review in the healthcare system (Ministry of Finance, 2019), there is a significant proportion of people who care for relatives without attendance service benefit.

In 2019, 6.0 % of the population aged 65+ received care in an institution and 5.8 % received care at home. The share of the population that received cash benefits represented 8.7 %.

As regards accessibility to the LTC services, Slovakia suffers from low capacities in residential care facilities, low accessibility of home care, and low support of informal carers (Ministry of Finance, 2019)[972], the financial support has been considerably increased over the last three years, the latest occasion being in July 2020. The number of people on waiting lists for homes for older people and specialised facilities (residential care) exceeded the number of

[970] OECD, *Measuring social protection for long-term care in old-age*. OECD Publishing, Paris, 2019.
[971] https://e.dennikn.sk/755618/ani-zlych-opatrovateliek-uz-nie-je-dost-za-tie-peniaze-to-nebudu-robit-ani-ukrajinky-ako-pomahame-starym-a-chorym/
[972] Ministry of Finance, *Review of spending on healthcare sector*. Value for Money Unit, 2019.

available places by 30 % in 2018. In social service facilities, the number of people on waiting lists exceeded the capacities by 13 %. Furthermore, as financing of home care relies on EU-27 funds, they are provided on a project basis, where various factors come into play. In 2016, 28.0 % of households in need of LTC did not use professional home care for financial reasons and 9.3 % did not use it because it was not available.

## 2.2 Quality

The Act on Social Services no. 448/2008 defines the quality standards for social services that apply also to long-term care social services. These standards do not apply to informal carers because they are not formally recognised as providers of social services. The Act defines four dimensions of quality for social services that relate to the situation of the care recipients and the condition of social services provision. They include respect for human rights and freedoms, procedural conditions, personal conditions and operational conditions.

The four dimensions are accompanied by twenty one criteria. In the component labelled 'respect for human rights', the Act defines the following criteria: basic human rights and freedoms, the social status of care recipients (including recipient's identity, integrity, or independence), family and community. In relation to the component labelled 'procedural conditions', criteria include definitions of vision, strategy, and objectives of the social service, definitions of procedures and conditions of social service (what and how it is provided), and rules and methods to identify satisfaction with the provision of the social service.[973] The last two components - personal conditions and operational conditions - contain criteria, which describe ways to promote adequate personal and technical conditions of social services, including, for example, a system of qualification requirements or a system of supervision.

The criteria are weighted according to their importance for care recipients and providers. Criteria, which are the most important to care recipients, have a weight of 4. Criteria, which are very important for both recipients and providers, are assigned the value of 2. Lastly, criterions, which are important for both recipients and providers, have value of 1.[974] The aim of this scheme is to support a recipient-oriented assessment of the quality by giving greater emphasis to the client's view and experiences.[975] In addition, each criterion is operationalised into several indicators that are directly identifiable. These indicators serve as a tool for quality assessment carried out by the Ministry of Labour, Social Affairs and Family.[976]

An overall quality assessment is a result of the weighted average of criterions and indicators, expressed as a percentage. According to the Act on Social Services, a provider of a social service must reach at least 60 % of the total score in order to meet quality criteria.

[973] These rules and methods include, for example, a system for reporting complaints or tools for feedbacks and suggestions. As such, it does not mean that users' satisfaction must be regularly assessed.
[974] The value of 2 is not defined in this classification.
[975] For example, the criterion 'respect for social status' is assigned the value of 4, indicating its fundamental role for care recipients. On the other hand, the criterion 'provision of information to people searching for social service' have the value of 2.
[976] Each indicator can take one of three values: he value of 3 indicating that 'it fully complies with requirements'; the value of 2 indicating that 'it partly complies with requirements'; and the value of 0 indicating that 'it does meet requirements at all'.

Although the standards of quality for social services were defined in 2008, regular assessment of quality has been postponed several times. This is because many providers were not able to fulfil all criteria, often as result of problems with existing financial support. Furthermore, the Ministry of Labour, Social Affairs and Family itself was not prepared to implement such an evaluation. Recently, the Ministry of Labour, Social Affairs, and Family has developed a methodology for the implementation of quality requirements that could help providers as well as a methodology for administering and processing the quality assessment. The national project 'Quality of Social Services', funded from the Operational Programme 'Human Resources', has been implemented since June 2019.[977] The aim is to provide methodological support and guidance to public and non-public providers of social services as well as evaluators.[978]

A regular assessment was launched in September 2019. As such evaluation is required by the law, it represents a legal obligation for the Ministry of Labour, Social Affairs and Family (as evaluator) and social services providers, including public and non-public providers. The assessment covers all four dimensions, 21 criterions and related indicators.

In the healthcare sector, there are no specific standards of quality in relation to long-term care activities in healthcare facilities (for example in long-term care departments of the medical clinics, or in nursing homes). Recently, new standards for diagnostic and therapeutic practices have been developed by the Ministry of Health, with the aim to ensure that all patients have access to health care of equal quality. Since 2019, 31 new standard diagnostic and therapeutic practices have come into force, including practices in the field of nursing and palliative care.[979]

## 2.3 Employment (workforce and informal carers)

The number of personal carers at home decreased in the period 2011-2016, while it increased for those working in institutions.[980] The number of LTC workers per 100 people aged 65+ is among the lowest in the EU-27 (1.5 worker per 100 older people), representing less than half the EU-27 average. It confirms the fact that care provided by family members remains the main form of LTC in Slovakia.

The tenure, defined as number of years LTC workers spend with their employer, is high in Slovakia compared to other countries. In 2016, the median tenure was about six years, above the EU-27 average. Taking into account the low number of LTC workers in relation to the population aged 65+, Slovakia faces greater recruitment issues than retention issues. According to experts, a lack of professionals who provide long-term care at home represent a major problem.[981]

[977] https://kvalitasocialnychsluzieb.gov.sk/en/home/
[978] Evaluators are experts from the Ministry of Labour, Social Affairs and Family or experts from an external environment who cooperate with the Ministry in the process of evaluation.
[979] https://www.health.gov.sk/Clanok?standardne-diagnosticke-postupy
[980] Data in this section come mainly from OECD (2020), 'Who Cares? Attracting and Retaining Care Workers for the Elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020. https://doi.org/10.1787/92c0ef68-en
[981] https://e.dennikn.sk/755618/ani-zlych-opatrovateliek-uz-nie-je-dost-za-tie-peniaze-to-nebudu-robit-ani-ukrajinky-ako-pomahame-starym-a-chorym/

Most LTC workers are women: they account for more than 90 % of the total in 2016. The majority of LTC workers have a medium level of education, including upper secondary education and post-secondary, non-tertiary education (ISCED 3-4). The proportion of care workers with a medium degree of education is one of the highest among the EU-27 countries (OECD, 2020, Figure 2.12).

Non-standard employment is not very widespread in the LTC sector. The share of temporary employment is less than 10 %. Shift work is experienced by less than 40 % of the LTC workforce, far below the EU-27 average.

According to the *Strategy of long-term social and health care in Slovakia* (Levyová et al, 2019)[982], published under the remit of the Office of Plenipotentiary of Government for Development of Civil Society, the long-term care workforce face several important challenges, including inadequate remuneration (taking into account how demanding LTC work is), difficulties to maintain the staff of LTC facilities, and a high workload.

With regards to informal carers, they carry out a significant amount of long-term care in Slovakia. Informal carers can claim for attendance service benefit. The average monthly number of people receiving attendance service benefit in 2019 was 57,048. People of working age accounted for 59 % of all recipients (Ministry of Labour, Social Affairs, and Family, 2019).[983] It is estimated that the actual number of informal carers is higher than the number of benefit recipients (Ministry of Finance, 2019), because attendance service benefit is paid only to caregivers who care for people diagnosed with severe disabilities, who represent approximately 20 % of the people who are in need of LTC. As a result, there are caregivers who provide long-term care without financial support from the state.

Informal carers can take leave and recover from caring duties by using so-called 'respite care' services. The aim of respite care services is to help informal carers by providing a period for recovering to help maintain their mental and physical health. It is provided for a maximum period of 30 days per year and is organised by the municipalities. During the period of respite care, municipalities have to provide substitute social services for people with disabilities. During this 'break', carers receive the nursing allowance. The usage of the respite care service is low in Slovakia.[984] In addition to 'respite care', the state supports people receiving the nursing allowance by paying contributions to old-age and invalidity insurance schemes.

Recently, the situation of informal carers has been addressed by the programme statement of the new government, established in March 2020 on the basis of the 2020 general election. The government has declared that it will establish a system of skills validation for informal carers and it will consider introducing supervision for informal carers, as well as a new 'benefit for recreation'.

[982] Levyová, M. et al., *Strategy of long-term social and health care in Slovakia, 2020.*
[983] Ministry of Labour, Social Affairs and Family, *Report on the social situation of the population of the Slovak Republic in 2018*, Bratislava, 2019.
[984] https://e.dennikn.sk/755618/ani-zlych-opatrovateliek-uz-nie-je-dost-za-tie-peniaze-to-nebudu-robit-ani-ukrajinky-ako-pomahame-starym-a-chorym/

## 2.4 Financial sustainability

Public LTC spending represented 0.8 % of GDP in 2019, which was below the EU-27 average (1.7 %). According to the Ageing Working Group reference scenario[985] of the 2021 Ageing Report[986], it is projected to increase by 162 % (1.3 p.p.) by 2050, reaching 2.1 % of GDP. Based on the risk scenario, public spending is expected to grow by 313 % (2.5 p.p.) and reach 3.3 % of GDP in 2050.

Public LTC spending was unevenly distributed between expenditure on home care (9.2 % of total LTC expenditure), residential care (50.4 %) and cash benefits (40.4 %). However, the projections show that the share of LTC expenditure on residential care (in total LTC spending) will increase by 10.7 p.p., while the share of expenditure on home care is expected to increase by 3.1 p.p. Should this happen, there would be a strong pressure on the capacities of LTC services, which are already very limited.

Nonetheless, the financial sustainability of the LTC sector is threatened by the projected demographic development and related growing needs for LTC. In addition, there are low levels of coordination between social and health long-term care services. There is a consensus that the LTC services require deep reforms, both in term of financing and coordination.

Informal carers represents a 'cheaper' solution in terms of public finances, as they can claim for attendance service benefit only. Moreover, it is estimated that the real number of informal carers in Slovakia is quite a bit higher than the official number of recipients of attendance service benefit (Ministry of Finance, 2019: [108]). As result, their work saves public resources in two ways: they do a lot of irreplaceable work at lower costs (and without adequate remuneration) and not all of them claim for public support.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Almost all the challenges identified in this report relate to all age groups. In particular, low capacities both in residential care and home-based care, a weak coordination between social and health systems, work overload and the shortage of qualified staff represent big challenges, irrespective of the age of the dependent person.

The ongoing process of deinstitutionalisation of care for people with disabilities represents one of the biggest challenges. A critical view of de-institutionalisation of social services, and especially services for people with disabilities is widespread among NGOs and experts too.[987]

# 3 REFORM OBJECTIVES AND TRENDS

The affordability, accessibility, financing and the quality of LTC services has been addressed by several measures in the period 2017-2020.

[985] Assuming no changes in the structure of benefits' provision and similar cost profiles

[986] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.

[987] See an Open Letter of the NGOs to Prime Minister, https://www.socia.sk/otvoreny-list-predsedovi-vlady-sr-ing-petrovi-pellegrinimu-o-stagnujucom-procese-deinstitucionalizacie/.

The financing of social services, including LTC services, was partially changed in 2018, when the amendment of the Act on social services came into force. Financial contribution paid by the state to social service providers came to be granted according to the degree of dependency of each client. The contribution - granted from the budget of the Ministry of Labour, Social Affairs, and Family - is paid to the social service facilities who provide services for people dependent on assistance of another person (residential and semi-residential care: social service care homes, care homes for older people, specialised care facilities, nursing care facilities, supported living homes, rehabilitation centres, day care centres).[988] The financial contribution is paid with the aim to co-finance the economic costs of the providers related to wages and social contribution of employees. Such steps enhanced the sustainability of social service provision (in particular, the provision of LTC services) and it also contributes to their affordability.

Multi-source financing of social services was also reinforced by introducing payments for health nursing care in the social service facilities, covered by public health insurance. This change came also into force as of January 2018.

In 2019, the new concepts 'institutional health after care' (*následná ústavná zdravotná starostlivosť*) and 'institutional nursing aftercare' (*následná ústavná ošetrovateľská starostlivosť*) were defined by the Act on health care. Institutional aftercare represents an intermediate step between hospitalisation and outpatient health care. It can be provided for three months in hospitals' wards providing health care for long-term patients or palliative care, hospices, nursing homes, and other facilities. In order to meet future demand, the number of beds for institutional aftercare should be doubled by 2030 (Ministry of Finance, 2019).

Social protection related to LTC has also undergone some changes. In 2019, a new social benefit - benefit for long-term care for a sick relative (*dlhodobé ošetrovné*) – was introduced. Benefit for long-term care for a sick relative complements a similar social benefit (benefit for caring for a sick relative) that is already in place. It allows people to care for relatives who leave hospital in a poor health or are in need of palliative care for a maximum of 90 days. It is intended for people paying sickness insurance contributions. The amount of the benefit was set as 55 % of the average wage. This legislation will come into force as of January 2021. It is expected that 400 people per month will claim for the new benefit.

[988] The term 'dependency on assistance of another person' (*odkázanosť na pomoc inej osoby*) is an equivalent to the term 'dependence'. Defined by the Act on social services, it refers to persons who rely on assistance with activities of daily living and/or instrumental activities of daily living. Degree of dependency on assistance of another person represents a criterion for assessing entitlements to the social services.

The financial support of informal carers has significantly improved. In the period 2016-2018, the amount of the attendance service benefit has been increased several times. In 2018, attendance service benefit for people of working age reached the level of the minimum wage. Other recipients, including carers of retirement age and parents of small children, benefited from the increases as well.

The quality of social services (and LTC services in particular) have become an object of systematic action. Recently, an assessment of quality was launched (see Section 2.2).

All reforms have addressed – to some extent – the affordability, accessibility and sustainability of the LTC services. However, several challenges remain (see Section 2). They were also addressed by one of the Country Specific Recommendations, which Slovakia had in 2019.[989] It pointed out the need to enhance access to affordable and quality long-term care.

The COVID-19 pandemic has induced some reforms in the LTC sector. First, administrative and financial procedures concerning social services operations have been simplified by a series of decrees issued by the Ministry of Labour, Social Affairs and Family. Second, a financial contribution for facilities providing services to people in need of assistance from another person and facilities for older people has been increased. Third, financial benefit for caregivers was increased substantially (see footnote 7).

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

LTC in Slovakia, with its multiple shortcomings (weak coordination of LTC services, low capacities of residential and home care services, slow rate of deinstitutionalisation), will have to cope with increasing demand in the coming decades. In order to ensure that all older people have access to long-term care, the following opportunities for addressing the LTC challenges are recommended:

- to focus on the coordination of LTC services between the social and health care sector;
- to build systematically the capacity for home care in order to avoid dependency on a project-driven logic;
- to improve significantly capacities of home care as well as residential care;
- to make faster progress in the rate of de-institutionalisation of the services for people with disabilities;
- to increase funding of LTC services, enhancing their multi-source financing.

[989] http://data.consilium.europa.eu/doc/document/ST-10178-2019-INIT/en/pdf

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 5.4 | 5.5 | 5.4 | 5.1 |
| Old-age dependency ratio, 2019 | | 16.8 | 23.5 | 32.6 | 51.4 |
| Population 65+ (in millions), 2019 | Total | 0.7 | 0.9 | 1.1 | 1.5 |
| | Women | 0.4 | 0.5 | 0.7 | 0.8 |
| | Men | 0.2 | 0.3 | 0.5 | 0.7 |
| Share of 65+ in population (%), 2019 | | 12.1 | 16.0 | 20.9 | 29.4 |
| Share of 75+ in population (%), 2019 | | 5.2 | 6.1 | 9.5 | 14.6 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 16.3* | 17.9 | | |
| | Women | 18.0* | 19.7 | 20.8 | 23.4 |
| | Men | 14.1* | 15.7 | 17 | 19.7 |
| Healthy life years at the age of 65, 2018 | Total | 3.1* | 4.4 | | |
| | Women | 2.8* | 4.6 | | |
| | Men | 3.3* | 4.0 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 493.0 | 578.2 | 680.0 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 273.5 | 368.6 | 511.0 |
| | Women | | 174.2 | 226.8 | 301.3 |
| | Men | | 99.3 | 141.8 | 209.6 |
| Share of potential dependants in total population (%), 2019 | | | 9.0 | 10.6 | 13.2 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 30.8 | 32.1 | 33.6 |
| Share of population 65+ in need of LTC** (%), 2019* | | 38.7 | 37.0 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 6.0 | 6.5 | 7.9 |
| Share of population 65+ receiving care at home (%), 2019 | | | 5.8 | 6.3 | 8.3 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 8.7 | 9.2 | 10.2 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 38.2 | 39.9 | 48.2 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 28.4 | 28.7 | 30.4 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 55.4 | 50.9 | | |
| | Women | 57.5 | 52.7 | | |
| | Men | 51 | 47.1 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 6.9 | 5.4 | | |
| | Women | 7.9 | 6.3 | | |
| | Men | 5.3 | 4.0 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 28.0 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 9.3 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 692.7 | 753.6 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 1.6 | 1.5 | | |
| | % Women | | 93.3 | | |
| Share of population providing informal care (%), 2016 | Total | | 7.9 | | |
| | Women | | 9.1 | | |
| | Men | | 6.6 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 23.9 | | |
| | Women | | 27.4 | | |
| | Men | | 18.6 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 0.2 | 0.8 | 1.2 | 2.1 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 0.2 | 0.8 | 1.5 | 3.3 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 32.6 | 50.4 | 54.6 | 61.1 |
| Public spending on home care as % of total LTC public spending, 2019 | 43.9 | 9.2 | 10.1 | 12.3 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 23.5 | 40.4 | 35.3 | 26.6 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 0.0 | 0.0 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.5 | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | - | 0.0 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.0 | - | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# FINLAND

***Highlights***

- *According to legislation, everyone is entitled to adequate care and the municipalities are responsible for providing in-kind-services of long-term care (LTC) to their residents. However, poorer municipalities, with a greater number of frail older people will have a hard time providing LTC-services for their population.*
- *Cash services include informal care support (municipal), care allowances and reimbursements for medications (from the Social Insurance Institution) and tax deductions for services (from the tax authorities).*
- *In 2019, the proportion of 65+ year olds in Finland was 21.8 % and the proportion of 75+ year olds was 9.3 %. There are substantial differences between the different Finnish municipalities and regions with regards to their old-age dependency rates, and these differences will most likely continue to grow.*
- *Care personnel in Finland is well trained, but the insufficient number of staff might become a growing problem.*
- *Since care must also be provided by relatives and friends, the possibility of combining work and care should be further developed.*

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends

The Finnish population will be ageing more quickly than populations in the other EU-27[990] Member States. In 2019, the share of population aged 65 and over to population aged 15 to 64 years old in Finland was 35.1 % compared to 31.4 % in the EU-27.[991] In 2030, the Old-age dependency ratios will be 42.2 % and 39.1 %, respectively. Whereas the pace of population aging will level off in Finland after 2030, it will accelerate in many other Member States. Consequently, after the year 2050, the Old-age dependency ratio in Finland (48.0 %) will be lower than the EU-27 average (52.0 %).

There will be substantial regional disparities in the old-age ratio between different Finnish municipalities and regions. In 2040, the share of 65+ year olds in relation to the 15-64 population will be 46 % across the whole country, 35 % in the capital area and around 55 %

[990] EU-27 refers to the current 27 Member States of the European Union.
[991] All data used in the text come from Section 5 'Background statistics' unless explicitly stated otherwise.

in Lapland and Northern Carelia. In some municipalities the share will be more than 100 %.[992]

The life-expectancy of Finns at the age 65 is rather high (20.6 years in 2019). The problem is that only 9.5 years (in 2018) of these years are healthy years. Usually, poor municipalities with high Old-age dependency ratios also have the largest frail older population. Since the municipalities are responsible for providing social services, including LTC services, the different municipalities are facing very different challenges depending on the share and health condition of their older residents. It has been estimated[993] that whereas the need for LTC services in all municipalities will grow by 50 % from 2015 to 2040, in one tenth of the municipalities the growth will be 70 %.

## 1.2 Governance and financial arrangements

The Finnish LTC care regime combines public, private and family-based provisions.[994] However, heavy care needs are most often taken care of by public providers, either wholly or partially. In 2019, public expenditure on LTC was 2.0 % (Section 5). According to the Constitution of Finland[995], section 19, everyone is entitled to adequate care. This promise is specified in a number of acts on public care services or in acts on private provisions. Thus, the provision of services is strongly anchored in legislation.[996] In principle, all services are universal and every older resident in a municipality is entitled to them. However, due to financial constraints and the care burden (see Section 1.1), there are substantial differences between the municipalities to the extent to which this principle of universalism is realised.

Even though LTC is a public responsibility, and though there is no legal obligation for children to take care of their parents other relatives (except for one's children under 18 years of age and one's spouse), families play an important role in LTC (see Section 2.3).

The municipalities are responsible for organising social services, including LTC, for their residents. They collect their own taxes to cover these service expenditures. The central government subsidises municipalities that are in economic difficulties. Most of the costs are covered by taxes, though some client fees are also collected. In 2014, clients paid 18.5 % of the costs of older people's services.[997] There are virtually no individual LTC insurance policies in Finland.

The municipalities can provide the services themselves or buy them from other municipalities or private service providers. They may also give vouchers to older people to buy services

[992] Taloussanomat, *44 suomalaiskuntaa joutui synkälle listalle*, 2020 [44 Finnish municipalities in a dark list', https://www.is.fi/taloussanomat/art-2000006404486.html. (accessed 6 April 2020)
[993] Kauppi, E., Määttänen, N., Salminen, T. and Valkonen, T., *Vanhusten pitkäaikaishoidon tarve vuoteen 2040* [The long-term care needs of the elderly population up to 2040]. KAKS, Helsinki, 2015.
[994] Kalliomaa-Puha, L. and Kangas, O., *ESPN Thematic Report on Challenges in long-term care: Finland*, European Social Policy Network (ESPN), European Commission, Brussels, 2018a.
[995] Constitution of Finland (731/1999).
[996] Acts on Social Welfare (1301/2014), Health Care (1326/2010), Old age Care (980/2012), Disability (380/1987), Care Allowances (570/2007) and Informal Care (937/2005). Private provisions are regulated by the acts on Private Social Services (922/2011), Family Care (263/2015) and Private Health Services (152/1990).
[997] Seppälä, T. and Pekurinen, M. (eds.), *Sosiaali- ja terveydenhuollon keskeiset rahavirrat* [Central financial sources in social and health care], Terveyden ja hyvinvoinnin laitos, Raportti 22/2014, Helsinki, 2018.

from private providers. Therefore, most of the costs of private service providers are also paid for by the municipalities.

## 1.3 Social protection provisions

In principle, access to LTC services should be based on people's needs and universally available for all who pass the needs-assessment. This assessment is based on the clients' self-assessed needs and expert evaluations. All above the age of 75, and all who receive the highest rate of care allowance for pensioners from the Social Insurance Institution, have the right to have a social-service needs assessment conducted within a specified period of time – generally, within seven days or immediately in urgent cases. According to law, there should be follow-up assessments.[998]

LTC services are granted on the basis of an individual service needs assessment. There are various indicators to measure a client's dependency and autonomy, but according to legislation the assessment should not build solely on these indicators but also on an overall assessment of the client's situation by the municipal social services.

LTC is supported by different forms of needs-based cash-for-care schemes such as informal care support or care allowances. A *care allowance* for pensioners - a cash benefit paid out by the Social Insurance Institution (Kela) - is intended to make it possible for pension recipients with an illness or disability to live at home, to promote home care and to reimburse pension recipients for any extra costs caused by illness or disability. The benefit is not means-tested but it is tested against the need of care. There are similar allowances for children and adults with disabilities. The care allowance is payable at three rates (in 2020 the amounts are: EUR 71.21, EUR 155.15 and EUR 328.07 per month for pensioners and EUR 93.05, EUR 217.13 and EUR 421.03 for children and adults), depending on the level of need for assistance, guidance, supervision and special expenses. The needs assessment is done by Kela.[999]

The *informal care support*, paid by municipalities, is a combination of cash benefits and benefits in kind. It is paid to a relative or a friend who provides care at home for an older person, or a person with a disability or a chronic disease. The condition for receiving this support is a contract between the municipality and the caregiver. The amount of the support is linked to the intensity of the care needed. If the caregiver is unable to work due to their heavy care obligations, the minimum amount is EUR 816.18 per month, and for less intensive care the minimum in 2020 is EUR 408.09 per month.[1000] The support is a taxable income and it accrues pension rights. These informal care benefits also include any municipal services that are necessary for the care-receiver to make care at home possible. These can consist, for example, of help with washing, medical care or meals on wheels. Official informal carers are also insured for accidents and, most importantly, get days off. A carer doing demanding care

[998] Act on Social Welfare.
[999] Kela [Social Insurance Institution of Finland], *Disability*, https://www.kela.fi/web/en/disability, 2020a (accessed 6 April 2020)
[1000] Kuntainfo [Information for Municipalities-newsletter], 2019, https://valtioneuvosto.fi/artikkeli/-/asset_publisher/1271139/kuntainfo-omaishoidon-tuen-hoitopalkkiot-vuonna-2020, (accessed 9 April 2020)

work gets three days off per month. The municipalities may also offer institutionalised care for certain intervals, in order to give the informal carers some rest[1001].

Finally, people can receive a *tax deduction* [*kotitalousvähennys*] for the expenses of caring for their or their spouse's children, parents or grandparents, which is handled by the tax authorities. And Kela provides reimbursements for any medical expenses.

## 1.4 Supply of services

Public LTC services can take different forms, and they can be provided via different channels either as in-kind or in-cash services or a combination of the two. In-kind services include LTC in health care centres (municipal), older people's residential homes (municipal or private), sheltered homes (municipal, private for profit, and non-profit providers), intensive sheltered homes (municipal or private) and day care/service centres (mainly public).

The publicly expressed target is to enable people to continue to live at home in spite of their LTC needs. In many municipalities, home services and home nursing are combined as *home care*. The proportion of 65+ or 75+ year olds who are entitled to home care (about 11 % for 65+ year olds and 22 % for 75+ year olds) has been rather constant throughout the 2010s[1002]. The national numbers are close to the self-reported use of home care services given in Section 5, wherein 12.8 % of 65+ year old Finns report using home care services.

Even though services supporting care at home are the priority, sometimes *sheltered housing* (where older people live in houses where they receive, e.g., cleaning and meal services) and *intensive sheltered housing* (where they have access to intensive 24-7 services, including medical services) are necessary.

About 60 % of all LTC recipients (93,000 in 2018) receive home services and the remaining 40 % are clients of 24-hour services. In 2018, the number of people employed in these two services were 16,000 and 41,000, respectively[1003]. The number of carers providing informal care support is 47,500, and it has been estimated that 350,000 Finns are providing care to their relatives[1004].

28 % of working-age people take care of their relatives and friends who are older or have, disabilities or an illness and are in need of care[1005]. Approximately 5 % of the 75+ population receive LTC from their relatives, and 70 % of these carers are women (STM, 2018). There are significant regional differences in the coverage of informal care (see Section 2.3).

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[1001] Kalliomaa-Puha, L. *Omaishoidon ja ansiotyön yhteensovittaminen* [Reconciling family care and employment], Sosiaali- ja terveysministeriö, Raportteja ja muistioita 60/2018, Helsinki, 2018. https://julkaisut.valtioneuvosto.fi/handle/10024/161286 (accessed 9 April 2020)

[1002] THL [Finnish Institute for Health and Welfare], *Vanhuspalvelujen tila, [the State of older care]*, 2019a https://thl.fi/fi/web/ikaantyminen/muuttuvat-vanhuspalvelut/vanhuspalvelujen-tila (accessed 4 April 2020)

[1003] THL, *Kotihoito ja sosiaalihuollon laitos- ja asumispalvelut 2018* [Home care, and institutional and housing services in social care 2018], Tilastoraportti 41/2019, 2019b. http://www.julkari.fi/bitstream/handle/10024/138808/Tr41_19.pdf?sequence=5 and isAllowed=y (accessed 4 April 2020),

[1004] Carers Finland, *Omaishoidon tietopaketti [Information package of informal care]*, 2020, https://omaishoitajat.fi/omaishoidon-tietopaketti/ (accessed 6 April 2020].

[1005] Silfver-Kuhalampi and Kauppinen, 2015.

The provision of LTC is a growing business. The increase in the number of older people and the dismantling of residential care (older people's homes and beds for LTC in health care centres)[1006] have opened the market for private LTC service providers. The municipalities have not been able to meet the growing demand, and they have tried to solve this problem by outsourcing the services in two ways: buying services from other municipalities/municipal consortia and buying services from private providers. Of all the LTC services, the municipalities provide 38 % themselves, 25 % are bought from other municipalities/municipal consortia and the remaining 37 % are provided by private providers. The lion's share of private providers are for-profit enterprises. They constitute 70 % of all entities in LTC housing services and 63 % of the personnel (data from 2016). The corresponding shares for non-profit organisations are 30 % and 27 % (Lith, 2018, p. 25).

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

The supply of LTC services has not entirely followed the demographic trends. The proportion of those over 65 years of age receiving LTC in institutions was 1.9 % and those receiving LTC at home was 13.3 % in 2019. Almost half of the Finnish municipalities state that there are not enough services available. In 2016, the share of households in need of LTC and not receiving professional homecare services because these services were not available was 12.6 % (Section 5).

Although the policy priority is to make it possible for the older population to stay at home as long as possible, there is a lack of adequate home care services. This problem is especially severe with regards to the provision of night-time services and the unequal geographic distribution of the services (THL, 2019b). In spite of the growing requirements, the coverage of housing services has remained constant throughout the last decade, and only the coverage of intensive 24-hours service housing has increased.

In order to ensure the affordability of and equal treatment in LTC, the central government regulates customer payments in municipal social and health care services. The goal of this policy is that the payments should be reasonable and keep the services affordable. The social and health services are either free of charge, or the customer fee is the same for everyone, or it depends on a person's income and family relationships.

Fees for the same type of LTC can vary depending on whether the care is considered to be residential care or service housing. In institutional LTC (older people's homes and health care centres), the fee is determined by the client's income and it can be as much as 85 % of the client's net income. However, at least EUR 110 per month must be left. In the case of service

[1006] THL, 2019b; Lith, P., *Palveluasumisen markkinat Suomessa*, Tilastollinen selvitys toimialan palvelukysynnästä. palveluntuottajista ja kiinteistöistä, 2018. www.hyvinvointiala.fi (accessed 6 April 2020)

housing, the fees are not fixed by law,[1007] rather they are decided by the service provider, i.e. the municipality or private LTC provider. There are also variations between the municipalities in the income limits forming the basis for customer fees and in customer vouchers to purchase services.

In Finland, there are many benefits available to both the carers and those receiving care. However, families in challenging situations may not have the resources to find the information they need. The application procedures may be too complicated for older people themselves, or even for relatives with low level of educational attainment. And the discretionary nature of the benefits may also lead to different outcomes depending on which municipality the client happens to live in (Kalliomaa-Puha and Kangas, 2018a).

Finns pay relatively high fees for their public services, even though the fees cover less than 10 % of the actual costs of the services. The fees vary according to the regularity of the service: in regular provision there are monthly payments which depend on the intensity of the service, the client's ability to pay and the size of the client's family. There are also fixed fees, for example EUR 11.40 per day, for substitute care for an informal carer. Some services are provided free of charge. There is also an annual maximum limit (EUR 577.66 in 2020) on out-of-pocket costs for medicine and health care to try to ensure the affordability of LTC. In 2016, the share of households in need of LTC and not using professional homecare services for financial reasons was 12.0 %.

It is also possible to be exempt from the fees, but this is rare. However, this situation will be changed as there are plans to extend the scope of free-of-charge services and to lower the out-of-pocket payments.[1008]

## 2.2 Quality

An important device to monitor the quality of care is the personal care and service plan, which specifies the services and support measures that a client should receive. It is a care contract between the client (or their representative) and the municipal authorities. The care contract is used in residential and home care settings.

At the institutional level, the National Supervisory Authority for Welfare and Health (Valvira) and six regional state administrative agencies supervise all the LTC provisions. They give directives and provide licenses to the private LTC producers which fulfil the basic requirements set in legislation[1009]. They also process complaints centrally, which enables them to get an overall picture and conduct broader investigations of the LTC if needed rather than just dealing with individual cases. In addition to this centralised supervision, the idea of solving problems locally has recently gained ground. Each institution must analyse any

[1007] The act on customer fees (1201/2020) was promulgated on 30 December 2020 and includes stricter regulations on customer fees for service housing (Act amending the Act on Social and Health Care Customer fees [Laki sosiaali- ja terveydenhuollon asiakasmaksuista annetun lain muuttamisesta], 1201/2020.)

[1008] STM [Ministry of Social Affairs and Health], *Sosiaali- ja terveyspalvelujen asiakasmaksulakia uudistetaan* [The Social and Health Services Customer Payment Act will be reformed], 2020. https://stm.fi/artikkeli/-/asset_publisher/sosiaali-ja-terveyspalvelujen-asiakasmaksulakia-uudistetaan (accessed 7 April 2020)

[1009] Act on Private social services (922/2011 laki yksityisistä sosiaalipalveluista), https://www.valvira.fi/sosiaalihuolto/yksityisen_sosiaalihuollon_luvat [Permissions for private social welfare services].

possible risks and draft a supervisory plan to prevent any problems from arising. The plan must be public and available to clients. This 'self-supervision' (*omavalvonta*) may not, however, work very well with clients in poor health, not to mention those suffering from dementia (Kalliomaa-Puha, 2018). But it is in line with the general idea of involving clients in the monitoring of the quality of the services that the Social Welfare Act provides. However, there are also unannounced inspections done by the supervisory authorities.

Sometimes the monitoring fails. In the winter and spring of 2019, severe shortcomings have been detected in older care: some of the privately run institutions providing sheltered care were found to have been mistreating older people and were subsequently closed down by the National Supervisory Authority for Welfare and Health. Many weaknesses of the system were pointed out, and older care became one of the topics discussed during the parliamentary elections in spring 2019[1010]. Prime Minister Sanna Marin's left-centre government passed a law on the nurse-client ratio in LTC and it came into force on 1 October 2020. The law will increase the number of personnel in 24/7 services by about 4400 by 2023, by increasing the ratio from 0.5, i.e. 5 nurses per 10 clients, to at least 0.7 and the interRAI system[1011] will be obligatory for all LTC institutions.[1012] According to the new law the needs of an older person are evaluated by an assessment system-RAI at the latest by 2023.

Monitoring and supervising informal care is quite difficult. If informal care is combined with municipal home services – as it often is – the employees of the home services may counsel the informal carers and also monitor the situation at home. However, the threshold suggests other forms of care is high because the supply is scarce.

The clients of the home services are now frailer than before, and the number of clients in need of constant services is growing. Some of the clients of the home services are frequent visitors to emergency medical care institutions. They require round-the-clock medical support, also at night and during weekends. Most of the clients of older care have a memory disorder and half of them live at home. The trend toward home services also means that more people die in their homes. Thus, there is a growing need for competent palliative and terminal care by the personnel of home services.[1013] The expert groups' recommendations on the provision and quality improvement of palliative care and terminal care services in Finland were issued on 17 December 2019.

The right to self-determination is a starting point in LTC services, and this is reflected in the legislation. However, it does not always materialise in practice. Plans to increase people's freedom of choice through vouchers and personal budgets could potentially guarantee self-determination. In previous voucher experiments, there were problems with overlapping

[1010] Kangas, O. and Kalliomaa-Puha, L., *ESPN Country Profile Finland 2018 – 2019,* unpublished and confidential to the European Commission, 2019.
[1011] interRAI is an international collaborative project to improve the quality of life of vulnerable people through a seamless comprehensive assessment system.
[1012] Hallituksen esitys [Governmetal Bill] 4/2020.
[1013] Until summer 2021, there is a group of experts in the Ministry of Social and Health working on palliative care, self-determination and euthanasia. The group on palliative care have already published some reports on the quality of palliative care, https://stm.fi/saattohoito.

services and the flow of information between all those involved.[1014] Allocating older people their 'own' social worker – as the Social Welfare Act provides – to help them find and coordinate services and to deal with the various authorities involved would improve their right to self-determination. However, there may be difficult ethical problems when the principle of self-determination and the quality of care are in conflict.

## 2.3 Employment (workforce and informal carers)

The workforce employed in official LTC in Finland generally consists of well-trained and educated professionals; they have permanent jobs, career opportunities and options for further education, though their wage level is not very high: nurses earn 90 %, practical nurse 69 % and care assistant 58 % of the average monthly earnings in the private sector (EUR 3386 in 2019)[1015].

There is a growing concern about the insufficient number of carers. There are around 50,000 professionals working in LTC: about 35,000 people in housing services and residential care and about 15,000 people in home care[1016]. Even those working in home care are trained personnel: one tenth of them are nurses and another tenth are trained home-helpers. The problem is not the training, but the fact that the number of staff is much smaller than required. The number of LTC workers per 100 people aged 65 and over was 7.6 in 2016. The number was higher than the OECD average (4.9) but much lower than in the neighbouring Nordic countries (Norway 12.7 and Sweden 12.4)[1017]. The government's decision to increase the staff-client ratio to 0.7 will make the lack of personnel more dramatic, as it will require 4400 more nurses. One obstacle to recruiting more employees is the relatively low pay in relation to the heavy workload. So far, the cash-for-care schemes have not yet led to the creation of a black labour market or an influx of (undocumented) migrant workers or undeclared workers - at least not on a large scale.

The well-being of the employees in LTC is good on average. However, the well-being of the employees in home care is diminishing. As the clients in home care are increasingly in poor health, the work involved is getting more onerous. Furthermore, the number of clients in home care has increased while the number of employees has decreased.[1018/1019]The employees are worried about the quality of care, do not sleep well and wonder whether they will be able to carry on until their own retirement (Vehko, Sinervo and Josefsson, 2017).

LTC still has a gender issue, whether formal or informal: 90 % of all the care providers are women. 350,000 people provide care for their relatives who are older, sick and/or have

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[1014] Vanninen, H., *Henkilökohtainen budjetti Keski-Uudenmaan valinnanvapauskokeilussa. Kokeilusta käytäntöön. Ikääntyneiden palvelut valinnanvapauden kynnyksellä – seminaari 30.2.2018. Terveyden ja hyvinvoinnin laitos*, Helsinki.
[1015] https://duunitori.fi/palkat/ (accessed 29 May 2020), 2018.
[1016] Vehko, T., Sinervo, T. and Josefsson, K., *Henkilöstön hyvinvointi vanhuspalveluissa – kotihoidon kehitys huolestuttava*, Tutkimuksesta tiiviisti. 11.kesäkuu 2017, Terveyden ja hyvinvoinnin laitos, Helsinki, 2017.
[1017] OECD, *Long-term care workforce: caring for the ageing population with dignity*, 2019, https://www.oecd.org/health/health-systems/long-term-care-workforce.htm (accessed 23 April 2020)
[1018] Kehusmaa, S., Vainio, S. and Alastalo, H. '*Ikääntyneet palvelun käyttäjät tuntevat olonsa turvalliseksi, mutta hoidon suunnitteluun osallistumisessa vielä kehitettävää. Tutkimuksesta tiiviisti 13, heinäkuu*' Terveyden ja hyvinvoinnin laitos, Helsinki, 2016.
[1019] A small decrease in the number of employees was observed in 2016, but in two years thereafter, their number had increased by 1, 000.

disabilities. Of these 350,000 carers, 60,000 provide highly demanding care. There are 47,500 informal carers (of which 70 % are women) who currently have a contract with their municipality and receive informal care support.[1020] The problem with this municipal care support is that its provision has been more dependent on the economic situation of the individual municipality than on the clients' need for help.[1021]

According to law, municipalities are encouraged to offer informal carers training as well as medical examinations. Since this is optional, the supply varies geographically.[1022] Providing rest for informal carers is crucial. Only one third of the informal care support receivers use the leave available to them, and one third use fewer days off than they are entitled to because they believe the substitute care would not be good enough or not be suitable for the care-receiver.[1023] This problem is well known and a lot has already been done to tackle it. Hiring substitute carers from among the family seems to be working well. Since not all families can supply a substitute carer, some municipalities have also implemented substitute carer pools (*sijaishoitajapankki*). While pension rights accrue for those carers who have signed an informal care agreement, the accrual rate is small. Proving this care also affects their careers. Therefore, caring periods scar the livelihood of working-age carers, often severely. These consequences are quite different for those carers who are already receiving a pension. If combining work and care is not possible, then perhaps the combination of services and cash for informal care support should be different for pensioners than it is for working-age carers (Kalliomaa-Puha, 2018).

## 2.4 Financial sustainability

In the coming two decades, the Finnish population will be ageing more quickly than the populations in the other EU-27 Member States. Needless to say, this will inevitably increase age-related social spending. Given these demographic calculations, the 2021 Ageing Report[1024] projects that the LTC spending will increase from the present 2.0 % to 3.5 % or even to 4.3 % in 2050 (Section 5). Since social spending already adds up to about 30 % of GDP and the public sector budget is in deficit – and the COVID-19 pandemic will increase this deficit by billions of euros – there are limited possibilities for increasing public spending on LTC.

The government is trying to solve the dilemmas in LTC by, on the one hand, digitalising public services and increasing their efficiency and, on the other hand, placing more emphasis on home care by relatives. According to the most recent data, 12 % of Finns provide informal care. Among women the proportion is higher (14 %) than among men (9.8 %).[1025] The

[1020] Carers Finland (2020)
[1021] Kalliomaa-Puha and Kangas (2018a); see also cases 70 and 71/2011 of the European Committee of Social Rights, which found the discretionary powers of the municipalities to be too wide.
[1022] Act on Informal Care (937/2005), Social Welfare Act (1304/2014); Kalliomaa-Puha (2019).
[1023] Kalliomaa-Puha, L. and Tillman, P. 'Äiti on aina äiti. Lasten omaishoitajien arjen haasteet' In *Haataja, A., Airio, I., Saarikallio-Torp*', M., and Valaste, M. (eds.), *Laura 573 5666 perheestä. Lapsiperheet ja perhepolitiikka 2000-luvulla,* Kelan tutkimus 2016, pp. 366-355.
[1024] European Commission and Economic Policy Committee, *The 2021 Ageing Report – Economic and budgetary projections for the 27 EU Member States (2019-2070)*, 2021.
[1025] Section 5 'Background statistics'.

strategy of informal care is double-edged. Having more informal home care will reduce public spending, but the flip side is that female labour force participation rates may diminish, which in turn would be detrimental to the long-term sustainability of the welfare state.

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Finland has focused on providing social and educational services to support the welfare of children with disabilities and their families. Municipalities are responsible for organising LTC services. However, too much depends on the municipality where the child happens to live. This goes for people with disabilities of all age groups. The growing old-age dependency ratio will worsen municipal budgets (see Section 1.1) making it more difficult to provide LTC for those with disabilities or mental illnesses.

There has been a shift for the better in the understanding of self-determination and participatory rights of inmates of institutions or other receivers of LTC. However, the balance between restrictive measures and self-determination has not been fully understood in, for example child welfare institutions or institutions for those with learning difficulties.[1026] Making all institutions plan ahead is hoped to solve the problem: supervisory plans of all institutions and personal care and service plans (see Section 2.2) must nowadays include a section in which the possibilities to increase self-determination and participation of care receivers are explained.[1027]

# 3 REFORM OBJECTIVES AND TRENDS

There have been no major reforms to LTC in Finland during the period under examination (1 January 2017 – 1 July 2020).[1028] Indeed, there has been no action while everybody waits for the SOTE-reform, which will implement an entirely new structure in the Finnish social and health care system[1029]. The EU Commission, in its Country Specific Recommendations[1030], has urged Finland to finalise this reform, which has already been on the agenda of four successive governments. The idea is to transfer the responsibility for social and health care from the municipalities to newly created counties. Sanna Marin's left-centre government needs to continue this reform. However, the details of the government's plans for this reform are not yet clear.

The government has announced that it will implement new standards for the nurse-client ratio and reduce out-of-pocket payments. Furthermore, the 2019 scandals (see Section 2.2) in LTC institutions in private for-profit institutions in particular, accentuated the need for stricter

[1026] Vuorilampi, S. and Saramaa, M. *Itsemääräämisoikeuden toteutuminen kehitysvammahuollon asumis- ja laitospalveluissa vuonna,* 2017. Valvira, Helsinki 2019, Eduskunnan oikeusasiamiehen kertomus 2018, https://www.oikeusasiamies.fi/fi/toimintakertomukset (accessed 6 April 2020)
[1027] See for example the Child Welfare Act (417/2007, changed by Act 542/2019) and the Act on the services of intellectually disabled (519/1977, changed by Act 381/2016).
[1028] During the previous reign 2015-2019, a major project was implemented to develop home care and family care for older people.
[1029] Kangas and Kalliomaa-Puha, 'Finland: The government's social and healthcare reform is facing problems', *ESPN Flash Report* 2018/2, European Commission, Brussels, 2018b.
[1030] http://data.consilium.europa.eu/doc/document/ST-10179-2019-INIT/en/pdf

quality screening. Therefore, the government passed a bill on 2 February 2020 on the nurse-client ratio in LTC (see Section 2.2).

Up to now, there are no indications that the LTC system had been affected by the COVID-19 pandemic.

***Planned reforms and on-going legislative process and debates***

- *The SOTE-reform, which will implement an entirely new structure in the Finnish social and health care system.*
- *The new law which came into force 1 October 2020 will implement new standards for the nurse-client ratio and reduce out-of-pocket payments. Furthermore, the InterRAI quality assessment system will be made obligatory for all LTC institutions.*

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

Though the unfinished SOTE-reform will have a bearing on all social and healthcare services, some trends are likely to remain that are related to access and affordability, quality of services, challenges in employment and sustainability.

*Access and affordability*: At the moment, the client fees are too high for some of the people in need of LTC, and payment for the various forms of services are treated differently without any clear reason. This will hopefully be at least partially fixed by the new act on client fees.[1031] A policy target is to avoid residential care and to make it possible for the population in need of LTC to live at home for as long as possible. Hence, the provision of adequate home care services must be guaranteed. This means that there will be new challenges with regard to both the quantity and the quality of the care provision.

[1031] The process is under way in parliament.

*Quality:* The quality in home care should be developed further with the help of experts with experience – as many municipalities already do. Allocating a designated social worker and carer to each care recipient would also tackle the problem of the growing complexity of the services, as they could aid in finding and coordinating the appropriate services and dealing with the various authorities involved.[1032] The clients receiving home services are frailer than before, and the amount of clients in need of constant services is high. So frequent visits by the care-personnel to the intimate and private sphere of the recipients' homes are necessary. There can be many people coming and going, which can be unpleasant for anyone but especially scary for people with memory disorders. And the current COVID-19 pandemic has highlighted the fact that a large number of visits by different people is also a health hazard for frail people. The trend towards home services also means that people now more commonly die in their homes. Thus, there is a growing need for competent palliative and terminal care by the personnel of home services. Frequently, people's needs at home are not medical but rather commonplace and could be improved by, for example, having designated care personnel. Giving more discretion to the personnel might also improve both their ability to cope with and their enjoyment of their work.

[1032] The purpose of the ongoing Future Health and Social Services Centres programme is to establish health and social services centres with wide-ranging services in Finland, which will ensure that services are provided seamlessly to people and that people are given help for their individual needs. It is also aimed at improving people's trust in public health and social services. Programme includes also development of client and service quidance to ensure the coordination of the appropriate services and dealing with the various authorities involved.

*Employment challenges:* Since the insufficient number of employees is a growing problem (see Section 2.3), the support for relatives and friends providing LTC needs to be developed further and the working conditions of professionals needs to be improved. The focus has been on those providing heavy care, but even more people are providing important care on a more sporadic basis. These people are often of working age and therefore their ability to combine work and care should be improved. The provisions for this in current labour legislation are not sufficiently clear, and they could be developed further (Kalliomaa-Puha, 2018). For instance, informal care support services could be better tailored to suit the needs of working age informal carers, and more could be done to guarantee their employment security and to compensate for unpaid leave as a result of providing informal care, especially if the labour force participation rates are to be kept high.

*Sustainability:* The old-age dependency ratio in Finland will rise from 35.1 % in 2017 to over 42.2 % by 2030. This increase in the old-age dependency ratio is due to both the increase in the number of people over 65 and the shrinking working-age population. Furthermore, an abrupt drop in the fertility rates adds severity to the problem.[1033] This means that there will be less carers to care a growing older population. There will be difficult prioritising problems in financing all the future tasks in the Finnish welfare state in general and in LTC in particular.

[1033] Kangas, O. and Kalliomaa-Puha, L. 'Can family policy save the welfare state? Some consequences of the steep decline in fertility in Finland', *ESPN Flash Report* 2019/58, European Commission, Brussels, 2019.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 5.3 | 5.5 | 5.5 | 5.3 |
| Old-age dependency ratio, 2019 | | 24.8 | 35.1 | 42.2 | 48.0 |
| Population 65+ (in millions), 2019 | Total | 0.9 | 1.2 | 1.4 | 1.5 |
| | Women | 0.5 | 0.7 | 0.8 | 0.8 |
| | Men | 0.4 | 0.5 | 0.6 | 0.7 |
| Share of 65+ in population (%), 2019 | | 16.5 | 21.8 | 25.8 | 28.2 |
| Share of 75+ in population (%), 2019 | | 7.8 | 9.3 | 13.7 | 16.0 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.7* | 20.6 | | |
| | Women | 21.5* | 22.3 | 23.3 | 25.1 |
| | Men | 17.5* | 18.8 | 19.8 | 21.7 |
| Healthy life years at the age of 65, 2018 | Total | 8.8* | 9.5 | | |
| | Women | 8.7* | 9.4 | | |
| | Men | 8.7* | 9.5 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 384.4 | 433.8 | 452.1 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 203.4 | 261.1 | 291.7 |
| | Women | | 119.9 | 150.6 | 166.8 |
| | Men | | 83.5 | 110.5 | 124.8 |
| Share of potential dependants in total population (%), 2019 | | | 7.0 | 7.9 | 8.6 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 16.7 | 18.3 | 19.5 |
| Share of population 65+ in need of LTC** (%), 2019* | | 16.3 | 18.1 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 1.9 | 2.2 | 2.7 |
| Share of population 65+ receiving care at home (%), 2019 | | | 13.3 | 15.3 | 19.0 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 13.9 | 15.6 | 18.5 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 91.1 | 95.6 | 111.4 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 83.1 | 85.3 | 94.7 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 80.7 | 70.4 | | |
| | Women | 90.7 | 79.4 | | |
| | Men | 61.6 | 56.5 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 12.8 | 6.2 | | |
| | Women | 16.1 | 6.8 | | |
| | Men | 8.8 | 5.5 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 12.0 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 12.6 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 1,155.6 | 1,190.0 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 8.2 | 7.6 | | |
| | % Women | | 89.7 | | |
| Share of population providing informal care (%), 2016 | Total | | 12.0 | | |
| | Women | | 14.0 | | |
| | Men | | 9.8 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 15.3 | | |
| | Women | | 16.5 | | |
| | Men | | 13.5 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 2.4 | 2.0 | 2.7 | 3.5 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 2.4 | 2.0 | 2.9 | 4.3 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 29.5 | 12.0 | 11.9 | 11.9 |
| Public spending on home care as % of total LTC public spending, 2019 | 56.4 | 76.1 | 77.6 | 78.2 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 14.1 | 11.9 | 10.4 | 9.9 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 1.7 | 1.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.7 | 0.7 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.3 | 0.3 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.1 | 0.0 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# SWEDEN

***Highlights***

- *The forecasted proportional increase of the population aged 65+ is lower than the EU-27[1034] average. In the coming decade, however, the proportion and number of people aged 80 years or older, a highly relevant population group for long-term care (LTC), will increase substantially. Assuming equal needs, LTC for people aged 80+ will increase by more than 50 % by 2030.*
- *The LTC system for older people is comprehensive and spending is higher than the EU-27 average. Coverage of residential care has significantly diminished, whereas home care has been relatively stable and informal carers have increased.*
- *The Swedish LTC system is decentralised, and municipalities have the main responsibility for institutional and home care. This, for example, means that eligibility criteria and serviced provided vary locally.*
- *LTC is tax-financed and out-of-pocket spending is around 4-5 % of total costs, which is low compared with most EU-27 countries.*
- *The working conditions of LTC workers and continuity within home care has for a long time been seen as problematic and is now been highlighted by the COVID-19 pandemic.*

## 1 DESCRIPTION OF MAIN FEATURES OF THE LONG-TERM CARE SYSTEM(S)

### 1.1 Demographic trends[1035]

In Sweden, as in many other countries, the process of population ageing is ongoing and expected to continue. A higher average age in the population is associated with a greater need for long-term care services, and an increased demand for LTC creates challenges for the organisation and financing of the LTC system. The older segment of the population is growing both in absolute and relative terms. In 2019, Sweden's total population size was around 10.2 million, out of which 2 million people were aged 65 and older. The share of the population aged 65+ was almost 20 %, and the share of the population aged 75+ was 9 %. These shares are projected to increase to 21.3 % (EU-27: 24.3 %) for those aged 65+ and 11.3 % (EU-27: 12.1 %) for those aged 75+ in 2030. Further, in 2050, the share of people aged 65+ is projected to be 23.5 % (EU-27: 29.3 %) and people aged 75+ to be 13.3 % (EU-27: 17.1 %).

[1034] EU-27 refers to the current 27 Member States of the European Union.
[1035] The demographic trends reported here come from the European Commission, Section 5 'Background statistics', if not otherwise stated.

The number of people potentially in need of LTC was 412,600 in 2019, and projected to increase to 487,600 in 2030 and to 570,200 in 2050. This corresponds to 4.0 % of the total population in 2019 being potentially dependent on LTC. The share is projected to be 4.4 % in 2030 and 4.6 % in 2050. However, the current share and projected changes are lower than in other EU-27 countries.

The ageing of the population also means that the share of people of working age is decreasing in relation to the share of people of retirement age. The Old-age dependency ratio was 31.9 in 2019, and this ratio is projected to increase to 34.4 in 2030 and 39.0 in 2050. These changes over time are relatively small in comparison to other EU-countries. In 2019, Sweden's Old-age dependency ratio was close to the EU-27 average of 31.4, but is expected to increase more modestly than the EU-27 average (39.1 in 2030; 52.0 in 2050).

To meet an increasing demand for LTC with a decreasing proportion of the population being (potentially) in the workforce puts a strain on the Swedish LTC system, which is largely tax-funded. However, the classical Old-age dependency ratio may lead to misleading conclusions, if we are to consider care needs and the care burden. The old-age dependency ratio takes into account people over 65 in comparison to people of working age. On average in Sweden, people's independency status starts to deteriorate more 'severely' at a much higher age, with, of course, a great deal of individual heterogeneity. This is also indicated in the healthy life expectancy figures. In 2019, remaining life expectancy at age 65 was 20.9 years in Sweden and 15.7 years were healthy years (without functional limitations) in 2018 (see Section 5).

LTC services are heavily concentrated on people aged 80 and above. Over half of all users of LTC are 80+ (Hashiguchi and Llena-Nozal, 2020)[1036]. Therefore, another way of projecting future need for LTC is to compare the share of people aged 80+ who receive formally provided care, either at home or in an institution. In 2019, 36 % of the population aged 80+ received LTC (home care services, long-term and short-term residential care), which corresponds to around 193,000 people. If the needs in this age group and the relative availability of care services remain the same, the number of people aged 80+ who receive LTC is projected to be around 291,000 in 2030. This is an increase of more than 50 % in just over a decade. (NBHW, 2020a, p. 15)[1037].

## 1.2 Governance and financial arrangements

Compared to many other Member States, Sweden has a comprehensive public LTC system for older people. LTC services in Sweden are regulated by the Social Services Act (2001:453) (SoL), the Act Concerning Support and Service for People with Certain Functional Impairments (1993:387) (LSS) and Health and Medical Services Act (SFS 1982:763) (HSL). The Social Services Act states that anyone who cannot meet their needs themselves or cannot have them met in other ways are entitled to support. This can be financial support (social assistance) and support to maintain their way of life in other ways. The Social Services Act

[1036] Cravo Oliveira Hashiguchi, T. and A. Llena-Nozal, 'The effectiveness of social protection for long-term care in old age: Is social protection reducing the risk of poverty associated with care needs?', *OECD Health Working Papers* No. 117, OECD Publishing, Paris, 2020, https://doi.org/10.1787/2592f06e-en

[1037] National Board of Health and Welfare, *Vård och omsorg om äldre. Lägesrapport 2020* [Health care and social care for older people. Status report 2020], National Board of Health and Welfare, Stockholm, 2020.

mentions ‘older people’ (without specification of age) and people with physical or mental functional limitations as groups that are entitled to support both in and outside their homes (SoL, 5 kap, 4-6§ [older people], 7-8§ [people with functional limitations]). The LSS encompasses people up to age 65. Those over 65 years of age who need support and do not already have support according to LSS are referred to the oldercare services.

There are no legal obligations or statutory requirements for adult children to provide care or economic security for their older parents. Still, a person that by their own choice wishes to care for a family member should be given recognition and support according to the Social Services Act (SoL).

At the national level, parliament and government set policy aims and directives, through legislation and economic incentives or steering measures. Health and medical care are organised and carried out at the regional level. The responsibility of carrying out the long-term care, both home care services (*hemtjänst*) and residential care (*Vård- och omsorgsboende* or *Särskilt boende* – the term varies locally) lies on the local (municipal) level. Certain forms of health care, for example rehabilitation and medical care carried out by nurses can also be given at home, ‘Home health care’ (*hemsjukvård*). Home health care is the responsibility of either the region or the local municipalities, but is increasingly taken over by the municipalities (NBHW, 2020a). Although responsibilities are divided, regions and municipalities are obliged to communicate in order to meet people’s needs. The Social Services Act states that when a person is in need of care from both social services and health care providers, an individual care plan shall be carried out in collaboration between the region and the municipality.

Sweden’s public expenditure on LTC is among the highest in the EU. In 2019, the public expenditure on LTC was estimated to be 3.3 % of GDP. The spending on residential care is higher than for home care-services but over time, the share of total spending on home care has gradually increased (NBHW, 2020a). The Swedish LTC services are tax-funded, and the financing of LTC is mainly carried out locally. Regions and municipalities finance around 90 % of the costs for healthcare and social care through taxation. Around 5 % is covered by national taxes. Out-of-pocket payments are relatively low, and users pay only a fraction (4-5 %) of the cost. Fees for LTC include care, rent, and meals. There is also a ceiling on fees. For 2020, the maximum amount charged for home care is SEK 2,125 (EUR 195) per month, and SEK 2183 (EUR 200) per month for residential care.

There is pronounced regional and local independence. At the national level, parliament and government set policy aims and directives, through legislation and economic incentives or steering measures, but priorities and decisions are often made at the local level. The municipalities vary considerably in population and character, therefore the financial sustainability for managing LTC differs between them.

## 1.3 Social protection provisions

All citizens are, if needed, eligible for health and social care services. Access to social care is based on a needs-assessment, as opposed to being means-tested. However, there are no national regulations on eligibility. Eligibility criteria, service levels, and the range of services

provided (for both home care and residential care) are decided locally. The evaluation is made by a needs assessor working for the municipality. The care can be carried out by either public or private providers, but the needs assessment is always made by the municipality. All assessments will be followed up within a year and revised if needed. Revisions to an assessment can also be made within a shorter time interval, for example after discharge from hospital care. The only exception is when a person has been granted residential care with 24-hour surveillance/care (*särskilt boende med heldygnsomsorg*), where no new assessments are made once the person has moved in. Since 2018, home-care services (hemtjänst) can be provided, without assessment, but in accordance with local guidelines. It is voluntary for the municipalities to introduce simplified home-care assessment. The model is aimed at increasing participation and autonomy for older women and men in how they would like their home care service provided.

For family carers of older people, there are two kinds of cash benefits available – attendance allowance (*hemvårdsbidrag/anhörigbidrag*) and carer's allowance (*anhöriganställning).* The provision of benefits is preceded by a needs assessment carried out by a municipal needs assessor. However, few municipalities provide these benefits; each municipality is free to decide whether to provide this benefit or not, to set the level of payment, eligibility criteria, etc. It is important to understand that at present, these kinds of support play a very minor role in the Swedish system as services in kind are prioritised.

## 1.4 Supply of services

There are two main forms of LTC: home care services and residential care in the form of special housing for older people. Home care services are most common, and include services such as grocery shopping, laundry, housecleaning as well as personal care services such as going for walks, cooking, dressing/undressing, using the toilet, and taking showers. Home health care services include medical care carried out by nurses and rehabilitation. Home care services can be complemented with home health care services and together these services can be offered around the clock. Residential care can be long-term or short-term arrangements. Residential care includes help with personal care, and health care services are available in the facilities. Day care services also exist, which are mainly social in nature.

In 2018, the distribution of LTC-services utilised by the population aged 80+ was as follows: 22 % of those aged 80+ used home care services, 11.9 % lived in long-term residential care facilities, 1.1 % lived in short-term care facilities and 1.3 % used day care services (NBHW, 2019)[1038]. The proportion of home care services in relation to residential care has changed significantly over time. This is further discussed below (Section 2.1).

Although public care providers are most numerous, the share of privately provided LTC has increased in recent decades (see e.g. Schön & Heap, 2018)[1039]. Several local municipalities have a 'customer's choice' system. That means that services are still publicly funded and the

[1038] National Board of Health and Welfare, *Vård och omsorg om äldre: Lägesrapport 2019* [Health care and social care for older people: Status report 2019], National Board of Health and Welfare, Stockholm, 2019.
[1039] Schön, P., and Heap, J., *ESPN Thematic Report on Challenges in long-term care: Sweden,* European Social Policy Network (ESPN), European Commission, Brussels, 2018.

local authorities specify the goals and quality required and sign contracts with multiple care providers. In 2019, the share of home care services that were carried out by private providers was around 17 %. Around 20 % of those living in institutional long-term care facilities lived in a private establishment. Of those living in short-term residential care facilities, around 8 % lived in private establishments (NBHW, 2020b)[1040].

In 2016, the number of LTC workers per 100 individuals aged 65+ was 12.4 % (Section 5). Also in 2016, the share of the population providing informal care was 22 %, out of which 5.4 % provided more than 20 hours of care per week (Section 5). A similar figure is also reported by the National Board of Health and Welfare (NBHW): in 2018, around 20 % of the population aged 18 and older provided informal care on a regular basis (NBHW, 2020a pp. 36). Although hard to measure, it has been noted that informal care has increased over the past few decades (NBHW, 2020a; Ulmanen and Szebehely, 2015)[1041].

# 2 ASSESSMENT OF THE LONG-TERM CARE CHALLENGES IN THE COUNTRY

## 2.1 Access and affordability

An important feature of the Swedish LTC system is that priorities and decisions are often made at a local level which means that both eligibility criteria and services provided vary both in home and residential care. At the same time, the Social Services Act applies throughout the country. The possibility for individuals to appeal a negative decision to the administrative courts contributes to the law being applied more uniformly.

Effective cooperation between healthcare and social care is seen as a prerequisite for a well-functioning LTC system. On 1 January 2018, a law (2017: 162) was introduced in Sweden on collaboration following discharge from inpatient care. The law promotes good care for the individual who, after discharge from inpatient care, need support from social services and municipal health care.

From a cross-national perspective, the LTC-system offers good coverage with a wide range of support services. For example, the number of available beds in nursing and residential care facilities is relatively high. In 2017, there were 1388 beds per 100,000 inhabitants, which was higher than in the other EU-countries with available data (Section 5). Nevertheless, the system has undergone substantial changes over the last few decades. These changes are mainly due to a shift from residential care to home care, a shift normally subsumed under the concept of ageing-in-place. This downsizing of residential care has to a much higher degree meant that only those most frail and dependent can access residential care. Among those aged 80 and above, the proportion receiving residential care has dropped by almost half from the early 1990s to 2017 – from slightly above 22 % in 1993 to around 12 % in 2017. The

[1040] National Board of Health and Welfare, *Statistik om äldre och personer med funktionsnedsättning efter regiform* 2019. [Statistics on older people and people with functional limitations according to provision form], National Board of Health and Welfare, Stockholm, 2020b. https://www.socialstyrelsen.se/statistik-och-data/statistik/statistikamnen/ socialtjanstinsatser-till-aldre/

[1041] Ulmanen, P. and Szebehely, M., 'From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden', *International Journal of Social Welfare* 24, 2015, pages 81-92.

proportion receiving formal home care has remained relatively stable at slightly above 20 % of the population (Schön and Heap, 2018).

In the population aged 65+, the self-reported use of home care services is quite low in Sweden (4.9 %)[1042] in 2019 (Section 5). It should however be remembered that the main usage of oldercare services is in the age group 80+. In 2016, 6.2 %[1043] of households in need of LTC abstained from formal home care services due to financial reasons. This is considerably lower than the EU-27 average (35.7 %). Also in 2016, 4.3 % of the households in need of LTC reported that they did not use formal home care services because they were not available.[1044] A possible explanation of this figure could be that these people had been assessed as being non-eligible.

As noted above, the formal LTC services are heavily subsidised and the out-of-pocket spending has been estimated to be around 4-5 %. A recent OECD working-paper (Hashiguchi and Llena-Nozal, 2020), models in detail the proportion of out-of-pocket payment in relation to income levels. The report clearly shows the comparatively low out-of-pocket payment in the Swedish system. According to the OECD modelling, 20 % of the old age population, by OECD defined as aged over 65, would be at risk of poverty after paying for the out-of-pocket costs of home care irrespective of different need levels.[1045]

The fact that this proportion does not increase for those with high levels of need, as compared with those with low levels, is likely to be because of the ceiling on fees, the ceiling being an important feature in many social service programmes. The ceiling is of course especially important for the costs of residential care (details on ceilings in Section 1.2). The OECD working-paper (Hashiguchi and Llena-Nozal, 2020, figure 3.11) shows that at median income levels, the out-of-pocket payment for residential care is lowest in Sweden among the countries compared. This is not to say that in individual cases the cost might be troublesome for those financially vulnerable, especially since most LTC recipients are much older than 65, and that people aged 80 and above have a much lower income than those aged 65-79. Still, in general, the issue of access has more to do with the eligibility criteria used by the municipality and the financial situation of the municipality.

## 2.2 Quality

Although there is no clear definition of quality in LTC services, this is highlighted in the legal documents regulating LTC services in Sweden: The Social Services Act (2001:453) (SoL), the Act Concerning Support and Service for Persons with Certain Functional Impairments (1993:387) (LSS) and Health and Medical Services Act (SFS 1982:763) (HSL). The

[1042] hlth_ehis_am7e
[1043] ilc_ats15
[1044] idem
[1045] The Swedish proportions at risk of poverty in the different figures of the OECD working-paper are not totally consistent. It is first stated (figures 5.1-5.3) that 20 % would be at risk of poverty irrespective of need level. Figures 5.6. and 5.7 instead report an increase to 30 % for those with moderate and high needs.

importance of good quality is emphasised in all three legislations, stated in almost identical wording (See further Schön & Fritzell, 2019)[1046].

There is a profusion of quality indicators within a national monitoring system called 'Open comparisons' (*Öppna jämförelser*)[1047]. They cover data from registers on issues such as waiting times, costs, and inappropriate drug use. The 'Open comparisons' also include a number of items from the User Satisfaction Survey, but as this survey has very high non-response rates, the reliability of these items is questionable. Response rate figures aside, there are items on quality in both home care services and residential care worth mentioning, including, for example: a) Share of older people with home care services who report that staff always or often have sufficient time to carry out their job; Mean value of number of staff members that a home care recipient meets during a 14-day period; Share of older people living in residential care who report that staff always or often have sufficient time to carry out their job; Waiting time for residential care; Assessment of food quality in residential care.

Consumer choice, and a trend in marketisation, has increased– especially with the Act on System of choice in the Public Sector (LOV) that was implemented in 2010. According to this act, private providers must have the opportunity to set up, and county councils and municipalities can contract out services to private providers (funded by the public system). The increase of for-profit providers in Nordic countries is analysed in depth by Szebehely & Meagher (2018)[1048], who note the establishment of big firms that now also build their own facilities, so making it very difficult to end a contract with a provider since a new premises must then be found.

One important aspect of quality, which has shown a clear negative trend for a long time, is continuity. For the care recipient, it is important to recognise the carer and as far as possible be cared for by the same staff. The number of carers a person who receives formal care meets has been increasing for long time. In 2007, a person with home care met, on average, as many as 12 carers during a period of 14 days, a number that further increased to 16 carers in 2019 (NBHW, 2020a).[1049] The quality within informal care is difficult – or impossible – to show, as no system for documentation or statistics on support to carers exists (Schön & Fritzell, 2019).

## 2.3 Employment (workforce and informal carers)

In 2017, it was estimated that 272,700 persons were employed in formal home care and residential care services, out of which around 86 % were women (Arbetsmiljöverket, 2020)[1050]. Sweden has high ambitions when it comes to educational qualifications within the

[1046] Schön, P., and Fritzell, J., *Mapping long-term care quality assurance practices in the EU: Sweden*, European Commission, Brussels, 2019.
[1047] Publications of results from Open Comparisons can be found at the National Board of Health and Welfare (NBHW) website. The website of the Swedish Association of Local Authorities and Regions (SALAR) provides both publications and a list of the indicators and their prevalences. An extended list of these indicators can be found in Schön and Fritzell 2019).
[1048] Szebehely, M and Meagher, G., 'Nordic eldercare – weak universalism becoming weaker?', *Journal of European Social Policy* 28(3), 2018, pp. 294-308.
[1049] That this measure not only is of importance for the feeling of security for those with home care but in fact maybe a matter of life and death is seen during the present COVID-19 pandemic. The spread of the virus is likely to be related to the number of carers you meet.
[1050] Arbetsmiljöverket, *Riskfylld arbetsmiljö - utmaningar för framtidens äldreomsorg Projektrapport Äldreomsorgen 2017-2019*, Arbetsmiljöverket, Stockholm, 2020.

LTC system. To have professionally trained staff, and – equally important – making them stay, is a key challenge within the Swedish LTC system. These ambitions are not easy to fulfil due to a shortage of nurses and other occupational categories. The shortage of nurses and other care personnel is also exacerbated by a high turnover. A survey among care workers found that almost half of them reported that they were seriously considering quitting the job, and this was more prevalent among those with higher educational credentials (Szebehely, Stranz and Strandell, 2017)[1051]. The reasons for considering quitting were associated with many different problematic and hectic working conditions, not least the time schedules and working hours – in other words a work-life balance problem. Another study by a trade union found a lower, but increasing, proportion of possible quitters within a three-year period (Kommunal, 2018)[1052].

The number of LTC workers per 100 individuals aged 65+ was 12.4 in 2016, which is a slight decrease from 12.8 in 2011 (see Section 5). A recent OECD (2020)[1053] report states that a decrease of LTC supply per 100 people aged 65+ may be less of a problem in Sweden due to increases in healthy life expectancy. This conclusion is problematic from several perspectives. First, again, LTC supply in relation to 65+ is a suboptimal indicator – LTC supply in relation to 80+ is more useful since LTC is heavily concentrated on this age group. For example, figures presented by Statistics Sweden[1054] show that 5.3 % of women and 4.4 % of men aged 65-79 receive home care services, while in the 80+ age group, 35.4 % of women and 26.8 % of men receive home care. Second, people aged 80+ is a population group growing more quickly than others. Third, the fact that healthy life expectancy has increased in recent years does not mean that the number of unhealthy years drop. This is exemplified in a study of life expectancy in Sweden, showing that although years free from disability increased in both men and women, the main part of men's increased life expectancy featured disability problems (Sundberg et al., 2016)[1055].

The stressful working conditions are further amplified by low pay and uncertain employment contracts. The average monthly full-time salary for an assistant nurse (*undersköterska*) within LTC is around 80 % of the average salary in Sweden and for care aides (*vårdbiträde*) slightly above 70 %. It should be noted that part-time employment and also employment by the hour is common. It is estimated that 25 % of the LTC workforce work is employed and paid by the hour (Strand and Szebehely, 2018)[1056]. Work stress and low pay for many in the LTC workforce has constantly been a challenge (Kommunal, 2018) and deteriorating working conditions over time has been reported (Strandell, 2020)[1057], something that is also reflected

[1051] Szebehely, M., Stranz, A., Strandell R. 'Vem ska arbeta i framtidens äldreomsorg? [Who is going to work in the future oldercare?], *Working paper/Department of Social Work*, Stockholm University, 2017.
[1052] Kommunal, *Personal som stannar. En rapport om arbetsmiljön i äldreomsorgen*, 2018.
[1053] OECD, 'Who Cares? Attracting and Retaining Care Workers for the Elderly', *OECD Health Policy Studies*, OECD Publishing, Paris, 2020, https://doi.org/10.1787/92c0ef68-en
[1054] https://www.scb.se/hitta-statistik/temaomraden/jamstalldhet/jamstalld-halsa/aldreomsorg/
[1055] Sundberg, L., Agahi, N., Fritzell, J. and Fors, S., 'Trends in health expectancies among the oldest old in Sweden, 1992–2011', *European Journal of Public Health* 26(6), 2016, pp. 1069–1074.
[1056] Strand, A., and Szebehely. M., 'Organisational trends impacting on everyday realities', *The Routledge Handbook of Social Care Work Around the World*, Routledge, London, 2018.
[1057] Strandell, R., 'Care workers under pressure – A comparison of the work situation in Swedish home care 2005 and 2015', *Health and Social Care in the Community* 28(1), 2020, pp. 137-147.

in sick leave statistics. The number of assistant nurses (*undersköterskor*) and other personnel in home care and residential care that are on sick leave is twice as high compared with all employees – a fact that is likely to decrease continuity and quality (NBHW, 2020a).

Historically, the comprehensive LTC provision in Sweden has relieved the strain of the care burden on families. The more recent reduction of residential care and the relatively high eligibility criteria have however increased the care burden on families. In a recent report (2020a), NBHW states that this is confirmed in several investigations. As noted above, around 20 % of the adult population provide informal care. Approximately 40-50 % of all informal care is given by older people. The care is quite often given to a person with extensive needs, for example a husband with dementia. Another reason for increased family care is the fact that a larger proportion of older people today have a partner or children compared to previous years. As stated above, there is neither a system for documentation nor any official statistics on carers and their support.[1058]

## 2.4 Financial sustainability

Sweden's LTC expenditure is among the highest in the EU-27. The projections from the 2021 Ageing Report (see Section 5) suggest that this spending will increase to 3.9 % of GDP (reference scenario) and 4.3 % (risk scenario) in 2030.[1059] In the short-term, estimates from SALAR (*Sveriges kommuner och regioner*) (2019)[1060] have highlighted that within LTC especially costs will increase for the municipalities during the next few years, due to demographic changes. Between 2018 and 2023, the costs are expected to increase slightly more than 10 %. The demographic change in the current decade is especially prevalent for those aged 80 and above, due to the very large birth cohorts born in the 1940s. As mentioned above, the older age group (80+) is the one most in need of LTC, and therefore most important for the sustainability of the present system.

As already noted, public spending on residential care is higher than for home care services: in 2019, 52.6 % of the total LTC spending was estimated to be on residential care (Section 5). National figures for residential care are slightlty different, in the most recent one for 2018, 57 % of LTC spending refers to residential care (*särskilt boende*).

The cuts in coverage, as reported above, have led to a higher involvement of both families and also pure market-based solutions. Given the very high labour force participation of women (who do the major bulk of both formal and informal care) in Sweden, a retrenchment of formal care would cause increased costs for many affected families, a work-life balance dilemma, and a lower labour supply among many affected households and thus a lower level of economic activity (i.e. GDP), and a lower tax base due to lower employment rates.

The pure market-based solutions have in Sweden benefited from a tax rebate on income (*RUT-avdrag*) introduced in 2007. This system, which is not only for services to older people,

[1058] The government has recently given a mission to the National Board of Health and Welfare to construct a basis for a national strategy to support relatives who care for older persons.
https://www.regeringen.se/regeringsuppdrag/2019/10/uppdrag-att-ta-fram-ett-underlag-for-en-nationell-strategi-for-anhoriga-som-vardar-eller-stodjer-narstaende-aldre-personer/
[1059] This increase is considerably lower than what was reported in the 2018 Ageing Report.
[1060] Salar (Sveriges kommuner och landsting) Ekonomirapporten oktober 2019. Om kommunerna och regionernas ekonomi.

means that you buy services from private providers but only pay half the prize (by using a tax rebate). Such services are used both to top up public services but also instead of regular home care. While such a system possibly leads to some positive financial benefits, it also creates a dilemma according to (Szebehely & Meagher (2018). The dilemma with this pure market-based, partly tax financed system concerns equality; a cornerstone in the Swedish system. Not surprisingly, the tax rebate favours those with higher incomes. Among peopled aged 65 and older, around 40 % use this system in affluent areas such as Danderyd, the municipality in Stockholm County with the highest median income in the country, whereas it is only used by around 5 % in many municipalities in Northern Sweden with much lower income levels (NBHW, 2020a).

## 2.5 Country-specific challenges regarding LTC for other age groups in need of care

Sweden has a system of support for people (below 65) with permanent functional impairments (LSS), see Schön and Johansson (2016)[1061] for a detailed presentation. This system has been heavily debated. Issues discussed within LSS include the level of personal assistance over recent years, and also concern human right issues, frauds within the system, and what specific types of needs should lead to the right to be entitled to personal assistance. In the aftermath of certain Supreme Court decisions, the state authority (*Försäkringskassan*) adopted tougher qualification rules to be eligible for personal assistance. The role of the state versus the municipalities was another central feature in the debate. The debated issues as well as increasing costs has led to several governmental inquiries. In turn, this later laid grounds for changes in the act to cover specific care elements within LSS for personal assistance. In January 2020, the government commissioned a new inquiry with the aim to strengthen the rights for personal assistance within LSS.

# 3 REFORM OBJECTIVES AND TRENDS

The government has taken measures to ensure that housing for older people is provided. In July 2016, the Government passed an ordinance on government grants for arranging and providing housing for older people. The grants are to encourage the renovation of existing residential properties for older people and the construction of new ones, as well as covering modifications to properties in order to enable older people to remain in their homes through improved accessibility and safety. SEK 2.2 billion was allocated for this purpose between 2016 and 2020. In April 2019, a new provision was introduced in the Social Services Act (2001: 453) which emphasises the municipalities' ability to set up special housing that is adapted and designed for older people who need care, which is not round-the-clock, but are no longer considered to be safe to stay in their own homes. This new form of housing is an alternative to the ordinary ones, where care needs are often extensive.

From January 1 2017 to the outbreak of COVID-19, there were few specific reforms. However, there has been support for increased welfare spending from the state to the

[1061] Schön, P and Johansson, L., *ESPN Thematic Report on work-life balance measures for people of working age with dependent relatives: Sweden*, European Social Policy Network (ESPN), European Commission, Brussels, 2016.

municipalities, aimed partly at increasing jobs within LTC. In a major decision from the spring bill in 2016, implemented yearly from 2017, SEK 10 billion (EUR 0.92 billion) was allocated (see Palme, Heap and Fritzell, 2016) [1062] with the intention to create job opportunities. The hiring of more assistant nurses was an example mentioned as a typical occupation that this support was aimed at. It must be remembered that municipalities have great sovereignty over how to deal with such general state support. In the years 2015 - 2018, the government allocated SEK 7 billion (EUR 0.64 billion) to increase staff within LTC. The NBHW (2020a) concluded that this has led to around 19,000 jobs being created, which in turn has increased security and quality for the care recipients as the employees get more time to spend with them. The most recent general additional support to the municipalities in 2020 (before the COVID-19 pandemic) of SEK 2.5 billion (SEUR 0.23 billion) was however, solely motivated by trying to diminish the risk of lay-offs within the welfare sector.

At the time of writing this report, the government has presented the spring budget 2020 and several extra budgets, which are almost totally related to the consequences of the COVID-19 pandemic. In these budgets, the government will increase the support to the municipalities with SEK 26 billion SEK, of which 12.5 billion will be permanent. This is not only for LTC but also for other services that the municipalities are in charge of, such as schools and public transport. Again, the sovereignty of the municipalities, and the uncertainty concerning loss of taxes due to lower employment, means that is impossible to state how much, if anything, will be allocated to LTC improvements.

However, on May 12, the Government presented a specific reform for the LTC workforce, the so-called oldercare lift programme (*äldreomsorgslyftet)*. LTC employees will be offered paid education to become, for example, an assistant nurse within the employment contract during paid working hours. This reform is expected to cost SEK 4.5 billion between 2020 and 2023. The Swedish Association of Local Authorities and Regions (SALAR) and the trade union Kommunal have complemented this reform by making an agreement stating that those taking part in the oldercare lift programme will be offered a permanent employment contract. The programme is expected to give 10,000 new permanent employment contracts for assistant nurses and care aides[1063].

[1062] Palme, J., Heap, J., and Fritzell, J, 'Significant increase in local welfare spending in Sweden', *ESPN Flash Report* 2016/58, European Social Policy Network (ESPN), European Commission, Brussels, 2016.
[1063] https://www.regeringen.se/pressmeddelanden/2020/05/10-000-nya-tillsvidareanstallda-inom-aldreomsorgen/

# 4 MAIN OPPORTUNITIES FOR ADDRESSING LTC CHALLENGES

The marked increase in the numbers and proportions of the oldest older people, and the thereby increased demand, is a key challenge for the Swedish LTC system – especially during the current decade. The financial structure of the LTC system makes affordability for older people a minor issue at present. The issue of access is tied to local self-government and the fact that the legislation is based on an individual needs assessment and local authorities decide on eligibility criteria, implies that access may be depending on the financial situation and prioritisation of the municipality. On a national level legislation and supervision are important tools to ensure equal access. Quality improvement is certainly within reach. The present pandemic has highlighted the importance of increasing continuity and the educational credentials of the staff. The recent proclaimed oldercare lift programme (see above) is no doubt a way forward if it is successfully implemented. Monitoring is a first prerequisite of quality improvement and given the extensive collection of data there is certainly good opportunities for improvement.

The sustainability of the Swedish LTC system is a challenge. Most evidence suggests that informal carers has increased somewhat in Sweden and this highlights the present lack of any systematic information on support for carers. This is obvious but also recognised. The government's mission to the NBHW to lay the groundwork for a national strategy (footnote 7) is a first step in that direction. The public LTC for older people is not a cost, it is a precondition for high levels of women's participation in the labour market, and thereby a precondition for economic growth and high standards of living.

The troublesome working conditions within LTC, both regarding employment contract, safety and stress, has been mentioned in many reports and is again highlighted during the present COVID-19 pandemic. The proclaimed older care lift programme is a direction to both increase continuity and the educational qualification of the staff. The intention is also to make jobs within this sector more attractive. It remains to be seen if this will have any long-term consequences for the organisation of and the working conditions within Swedish long-term care.

# 5 BACKGROUND STATISTICS

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 9.2 | 10.2 | 11.1 | 12.3 |
| Old-age dependency ratio, 2019 | | 26.7 | 31.9 | 34.4 | 39.0 |
| Population 65+ (in millions), 2019 | Total | 1.6 | 2.0 | 2.4 | 2.9 |
| | Women | 0.9 | 1.1 | 1.2 | 1.5 |
| | Men | 0.7 | 0.9 | 1.1 | 1.4 |
| Share of 65+ in population (%), 2019 | | 17.5 | 19.9 | 21.3 | 23.5 |
| Share of 75+ in population (%), 2019 | | 8.7 | 9 | 11.3 | 13.3 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.8* | 20.9 | | |
| | Women | 21.2* | 22.1 | 22.9 | 24.8 |
| | Men | 18.3* | 19.6 | 20.4 | 22.2 |
| Healthy life years at the age of 65, 2018 | Total | 12.9* | 15.7 | | |
| | Women | 13.4* | 15.8 | | |
| | Men | 12.2* | 15.6 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 412.6 | 487.6 | 570.2 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 203.2 | 262.7 | 334.3 |
| | Women | | 128.6 | 164.8 | 208.6 |
| | Men | | 74.5 | 97.9 | 125.7 |
| Share of potential dependants in total population (%), 2019 | | | 4.0 | 4.4 | 4.6 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 9.9 | 11.0 | 11.6 |
| Share of population 65+ in need of LTC** (%), 2019* | | 12.0 | 12.3 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 2.9 | 3.3 | 3.8 |
| Share of population 65+ receiving care at home (%), 2019 | | | 11.0 | 12.6 | 12.9 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 11.0 | 12.6 | 12.9 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 140.6 | 144.3 | 144.1 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 111.3 | 114.0 | 111.4 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 45 | 53.6 | | |
| | Women | 38.8 | 55.2 | | |
| | Men | 53.9 | 50.7 | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 5.4 | 4.9 | | |
| | Women | 6.2 | 5.5 | | |
| | Men | 4.6 | 4.3 | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 6.2 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 4.3 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | 1,276.7 | 1,388.0 | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 12.8 | 12.4 | | |
| | % Women | | 85.9 | | |
| Share of population providing informal care (%), 2016 | Total | | 22.0 | | |
| | Women | | 22.4 | | |
| | Men | | 21.6 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 5.4 | | |
| | Women | | 5.3 | | |
| | Men | | 5.4 | | |

**data not available for all Member States*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 3.6 | 3.3 | 3.9 | 4.6 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 3.6 | 3.3 | 4.3 | 6.3 |
| Public spending on institutional care as % of total LTC public spending, 2019 | 48.5 | 52.6 | 53.4 | 56.4 |
| Public spending on home care as % of total LTC public spending, 2019 | 47.9 | 44.7 | 44.3 | 41.8 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | 3.6 | 2.6 | 2.3 | 1.8 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | 2.7 | 2.7 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | 0.5 | 0.5 | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | 0.2 | 0.2 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | 0.0 | 0.0 | | |

*Note: break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not for this Member State*
**data not available for all Member States*

# EUROPEAN UNION 27

| 5.1. Demographics | | 2008 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Population (in millions), 2019 | | 438.7 | 446.8 | 449.1 | 441.2 |
| Old-age dependency ratio, 2019 | | 25.7 | 31.4 | 39.1 | 52.0 |
| Population 65+ (in millions), 2019 | Total | 75.7 | 90.5 | 108.5 | 130.2 |
| | Women | 44.5 | 51.7 | 61.0 | 72.1 |
| | Men | 31.2 | 38.8 | 47.5 | 58.0 |
| Share of 65+ in population (%), 2019 | | 17.3 | 20.3 | 24.2 | 29.5 |
| Share of 75+ in population (%), 2019 | | 8.0 | 9.7 | 12.0 | 17.1 |
| Life expectancy at the age of 65 (in years), 2019 | Total | 19.4* | 20.2 | | |
| | Women | 21* | 21.8 | | |
| | Men | 17.4* | 18.4 | | |
| Healthy life years at the age of 65, 2018 | Total | 8.4* | 9.9 | | |
| | Women | 8.5* | 10.0 | | |
| | Men | 8.4* | 9.8 | | |

**data for 2010*

| 5.2. People in need of LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of potential dependants (in thousands), 2019 | | | 30,816.1 | 33,716.4 | 38,072.1 |
| Number of potential dependants 65+ (in thousands), 2019 | Total | | 17,003.6 | 20,451.6 | 26,523.9 |
| | Women | | 10,857.7 | 12,755.6 | 16,445.1 |
| | Men | | 6,145.9 | 7,695.9 | 10,078.8 |
| Share of potential dependants in total population (%), 2019 | | | 7.0 | 7.7 | 8.8 |
| Share of potential dependants 65+ in population 65+ (%), 2019 | | | 19.0 | 19.2 | 20.8 |
| Share of population 65+ in need of LTC** (%), 2019* | | 27.3 | - | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.3. Access to LTC | | 2014 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Share of population 65+ receiving care in an institution (%), 2019 | | | 3.6 | 3.6 | 4.4 |
| Share of population 65+ receiving care at home (%), 2019 | | | 5.8 | 6.0 | 7.0 |
| Share of population 65+ receiving LTC cash benefits (%) 2019 | | | 8.8 | 9.4 | 10.5 |
| Share of potential dependants 65+ receiving formal LTC in-kind (%), 2019 | | | 49.2 | 50.4 | 54.8 |
| Share of potential dependants 65+ receiving LTC cash benefits (%), 2019 | | | 46.0 | 48.8 | 50.3 |
| Share of population 65+ in need of LTC** with a lack of assistance in personal care or household activities (%), 2019* | Total | 51.8 | - | | |
| | Women | 53.2 | - | | |
| | Men | 48.4 | - | | |
| Share of population 65+ who used home care services in the past 12 months (%), 2019* | Total | 11.0 | - | | |
| | Women | 13.1 | - | | |
| | Men | 8.3 | - | | |
| Share of households in need of LTC not using professional homecare services for financial reasons (%), 2016* | | | 35.7 | | |
| Share of households in need of LTC not using professional homecare services because services not available (%), 2016* | | | 9.7 | | |
| Long-term care beds per 100,000 inhabitants, 2017* | | - | - | | |

**data not available for all Member States;*
***at least one severe difficulty in ADLs and/or IADLs*

| 5.4. LTC Workforce | | 2011 | Most recent | 2030 | 2050 |
|---|---|---|---|---|---|
| Number of LTC workers per 100 individuals 65+, 2016* | Total | 4.2 | 3.8 | | |
| | % Women | | 90.8 | | |
| Share of population providing informal care (%), 2016 | Total | | 10.3 | | |
| | Women | | 11.7 | | |
| | Men | | 8.6 | | |
| Share of informal carers providing more than 20h care per week, 2016 | Total | | 22.2 | | |
| | Women | | 24.6 | | |
| | Men | | 18.5 | | |

**data not available for all Member States; EU average is the unweighted average for 23 countries in 2011 and 25 countries in 2016*

| 5.5. LTC expenditure | 2013 | Most recent | 2030 | 2050 |
|---|---|---|---|---|
| Public spending on LTC as % of GDP (reference scenario), 2019 | 1.6 | 1.7 | 1.9 | 2.5 |
| Public spending on LTC as % of GDP (risk scenario), 2019 | 1.6 | 1.7 | 2.1 | 3.4 |
| Public spending on institutional care as % of total LTC public spending, 2019 | - | 48.1 | 49.1 | 51.4 |
| Public spending on home care as % of total LTC public spending, 2019 | 28.4 | 25.5 | 26.1 | 26.4 |
| Public spending on cash benefits as % of total LTC public spending, 2019 | - | 26.4 | 24.8 | 22.2 |
| Government and compulsory contributory financing schemes as % of GDP, LTC Health, 2018 | - | 1.3 | | |
| Government and compulsory contributory financing schemes as % of GDP, LTC Social, 2018* | - | - | | |
| Household out-of-pocket payment as % of GDP, LTC Health, 2018 | - | 0.3 | | |
| Household out-of-pocket payment as % of GDP, LTC Social, 2018* | - | - | | |

*Note: 2013 data on public spending refers to EU-28; break in series for DE and DK in the System of Health Accounts*
*A '-' shows that data is available in general, but not on EU level.*
**data not available for all Member States*

# ANNEX I: GLOSSARY OF INDICATORS

## *Data Table – Description of indicators and other statistics*

The list of indicators for the Country Fiches was agreed by the Indicators Sub-group of the Social Protection Committee (ISG). The set of indicators and statistics aims at measuring: 1) demographics; 2) people in need of LTC; 3) access to LTC; 4) LTC workforce; and 5) LTC expenditure. Furthermore, the ISG has already provisionally adopted various indicators and background statistics for a framework to assess in a comparative manner the access to, quality and sustainability of long-term care (LTC) across the EU. While this framework is work in progress, the indicators that have already been selected are subsequently marked with a *. The current report applies the definition of long-term care, as agreed by the Social Protection Committee in 2014, namely:

'Long-term care is defined as a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care. The daily living activities for which help is needed may be the self-care activities that a person must perform every day (Activities of Daily Living, or ADLs, such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions) or may be related to independent living (Instrumental Activities of Daily Living, or IADLs, such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone)'

The main abbreviations used are:

| | |
|---|---|
| ADL | Activities of daily living, also referred to as personal care activities |
| AWG | Ageing Working Group of the Economic Policy Committee |
| EHIS | European Health Interview Survey |
| EU-LFS | European Labour Force Survey |
| EU-SILC | European Union Statistics on Income and Living Conditions |
| IADL | Instrumental activities of daily living, also referred to as household activities |
| SHA | System of Health Accounts |

## Demographics

**Population total and 65+ in million, share of 65+*, 75+*** are based on European demographic statistics. This administrative data originates either from the most recent census adjusted by the components of population change produced since the last census, or from population registers (source: Eurostat, demo_pjanbroad, demo_pjanind and proj_19np).

**Old-age dependency ratio** is defined as the ratio between the number of people aged 65+ and the number of working-age people (15-64) (source: Eurostat, demo_pjanind and proj_19ndbi).

**Life expectancy at the age of 65 (in years)** is the average number of additional years of life that a survivor to age 65 will live beyond the age of 65, on the basis of current mortality (source: Eurostat, hlth_hlyeand proj_19nalexp).

**Healthy life years (HLY) at the age of 65** measures the number of remaining years that a person aged 65 is expected to continue to live in a healthy condition (i.e. without any severe or moderate activity limitation caused by a health problem). Activity limitation is a dimension of disability capturing long-standing limitation in performing usual activities due to health problems (the so-called 'GALI' [Global Activity Limitation Instrument], included in EU-SILC). The HLY indicator is therefore also called disability-free life expectancy. This indicator is based on age-specific prevalence (proportions) of the population in healthy and unhealthy condition and age-specific mortality information. It is compiled separately by sex and calculated using the Sullivan method. Therefore, HLY is a composite indicator that combines mortality data with health status data (source: Eurostat, hlth_hlye).

## People in need of LTC

**Number of potential dependants in thousands and their share (for total population and population 65+)** shows the data used in the Ageing Report to identify the number of people who might need LTC. The population of potential dependants is based on an average of the last four years of EU-SILC data (2015-2018) on severe 'self-perceived longstanding limitation in activities because of health problems [for at least the last six months]' for people in private households, with the addition of national data on recipients of institutional LTC (who are dependent and who are not included the EU-SILC survey). For Bulgaria, Italy, the Netherlands and Luxembourg, their average includes only 2016-2018 due to a break in the series. For Germany, coverage refers to the social insurance funds' insurees only. The projections are based on the Ageing Working Group (AWG) reference scenario. This scenario assumes that half of the projected gains in life expectancy are spent without disability (i.e. demanding care) (source: Ageing Working Group and DG ECFIN, partly based on Eurostat, EU-SILC and partly on national data).

**Share of population 65+ in need of LTC*, defined as having at least one severe difficulty in personal care activities (ADLs) and/or household activities (IADLS)** is the preferred indicator of the ISG to estimate the number of people in need of LTC. For personal care activities, respondents are asked whether they have difficulties 'Feeding yourself/ Getting in and out of a bed or chair/ Dressing and un-dressing/ Using toilets/ Bathing or showering'.

Household activities include 'Preparing meals/ Using the telephone/ Shopping/ Managing medication/ Light housework/ Occasional heavy housework/ Taking care of finances and everyday administrative tasks' (source: Eurostat, EHIS, hlth_ehis_tadle).

## Access to LTC

**Share of population 65+ receiving care in an institution*** shows the coverage with publicly provided or funded residential care from administrative data. The numbers are reported by Member States to the AWG and relate to the public provision and financing of care only. Latest figures may not be comparable to data from past Ageing Reports due to reporting improvements. For Germany, coverage and population refer to the social insurance funds' insurees only (source: Ageing Working Group and DG ECFIN).

**Share of population 65+ receiving care at home*** shows the coverage with publicly provided or funded home care from administrative data. The numbers are reported by Member States to the AWG and relate to the public provision and financing of care only. Latest figures may not be comparable to data from past Ageing Reports due to reporting improvements. For Germany, coverage refers to the social insurance funds' insurees only (source: Ageing Working Group and DG ECFIN).

**Share of population 65+ receiving LTC cash benefits*** shows the coverage with publicly funded LTC cash benefits from administrative data. The numbers are reported by Member States to the AWG and relate to the public provision of cash benefits only. Latest figures may not be comparable to data from past Ageing Reports due to reporting improvements. For Germany, coverage refers to the social insurance funds' insurees only (source: Ageing Working Group and DG ECFIN).

**Share of potential dependants receiving formal LTC in-kind benefits** shows the combined coverage of home care and institutional care that is publicly provided or funded for potential dependants. The coverage is calculated as the share of care of in-kind (home and institutional) care recipients over the dependent population. The limitations in estimating the real number of recipients covered by the system as well as those inherent to using EU-SILC survey to estimate the overall dependent population will have consequences for the derived coverage rates. A first limitation is that EU-SILC is self-reported and, although the questions in the survey are defined so as to elicit the information in the most accurate way, it may still differ from an objective analysis of dependency status. While this will reduce the accuracy of the estimate to some extent, it will not in principle bias it in an upward or downward direction. A second limitation is that the EU-SILC variable used to define dependency status focuses on severe disability. However, very comprehensive LTC systems cover not only severe disability but also lower levels of disability, such as people who need help with Instrumental Activities of Daily Living (IADL). This biases the estimation of coverage upwards as it underestimates the dependent population. The high coverage rates for some Member States can be explained by the fact that, in these countries, coverage for these types of care includes non-severe disability as well as severe disability. The numbers are reported by Member States to the AWG and relate to the public provision and financing of care only. For Germany, coverage

refers to the social insurance funds' insurees only (source: Ageing Working Group and DG ECFIN).

**Share of potential dependants receiving LTC cash benefits** shows the coverage of publicly funded LTC cash benefits for potential dependants. The coverage is calculated as the share of cash benefit recipients over the dependent population. It has to be noted that people can receive both cash and in-kind benefits (including home care and institutional care benefits), resulting in double counting if the coverage of the three care settings is aggregated without adjustment. The limitations in estimating the real number of recipients covered by the system as well as those inherent to using EU-SILC survey to estimate the overall dependent population will have consequences for the derived coverage rates. A first limitation is that EU-SILC is self-reported and, although the questions in the survey are defined so as to elicit the information in the most accurate way, it may still differ from an objective analysis of dependency status. While this will reduce the accuracy of the estimate to some extent, it will not in principle bias it in an upward or downward direction. A second limitation is that the EU-SILC variable used to define dependency status focuses on severe disability. However, very comprehensive LTC systems cover not only severe disability but also lower levels of disability, such as people who need help with Instrumental Activities of Daily Living (IADL). This biases the estimation of coverage upwards as it underestimates the dependent population. The high coverage rates for some Member States can be explained by the fact that, in these countries, coverage for these types of care includes non-severe disability as well as severe disability. The numbers are reported by Member States to the AWG and relate to the public provision of care only. For Germany, coverage refers to the social insurance funds' insurees only (source: Ageing Working Group and DG ECFIN).

**Share of population 65+ in need of LTC with a lack of assistance in personal care or household activities *** estimates how many people have unmet needs for long-term care. People with at least one severe difficulty in personal care or household activities are asked whether they usually receive assistance, get enough assistance or have a lack of assistance in these activities (source: Eurostat, EHIS, hlth_ehis_tadlh).

**Share of population 65+ who used home care services for personal needs in the past 12 months*** shows the extent that older people have used formal home care services. Home care services refer to the provision of medical and non-medical in-home supporting care services for persons who, due to the physical or mental illness or disability or because of old age, cannot perform specific personal or household care activities or are confined to their own houses. It includes home-based services provided by a visiting nurse or midwife from a health institute, agency or association, or by a community organisation using professional or non-professional (volunteer) staff for care delivery (source: Eurostat, EHIS, hlth_ehis_am7e).

**Share of households in need of LTC not using (more) professional homecare services for financial reason or because the services needed are not available*** illustrates two of the five reasons why professional homecare services are not used by households with at least one member who would need help due to long-term physical or mental ill-health, infirmity or because of old age. The answer categories for the main reason are 'cannot afford it', 'refused

by people needing such services', 'no such services available', 'quality of the services available not satisfactory', and 'other' (source: Eurostat, EU-SILC, ilc_ats15)

**Long-term care beds per 100,000 inhabitants*** is administrative data. These density rates are calculated by dividing the absolute number of LTC beds in nursing and residential care facilities available in a given period by the respective population in the same period and then multiplying by 100,000 (source: Eurostat, hlth_rs_bdsns).

### LTC workforce

**Number of LTC workers per 100 individuals 65+*** is calculated by dividing the numbers of LTC workers in the formal care sector by the total population 65+, and then multiplying by 100 (source: OECD, based on EU LFS and administrative data).

**Share of population providing informal care*** is the share of respondents who provide care or assistance to one or more people needing help due to long-term physical or mental health illness, physical weakness or because of old-age. Only voluntary (unpaid) assistance is considered. The informal care can be provided by the person interviewed to household members and/or to people who are not household members (source: Eurostat, EU-SILC, ilc_ats17).

**Share of informal carers providing more than 20h informal care per week*** is the share of respondents who provide care or assistance to one or more people needing help due to long-term physical or mental health illness, physical weakness or because of old-age more than 20 hours a week. Respondents who reply positively to ilc_ats17 are asked in the survey whether they provide less than 10 hours of care, between 10 and 20 hours of care or more than 20 hours of care per week (source: Eurostat, EU-SILC, ilc_ats18).

## 5.1 Public LTC spending as % of GDP, current and projections

**Public spending on LTC as % of GDP (reference scenario)*** shows the current expenditure in the base year and the projections according to the 'AWG reference scenario'. This scenario combines the assumptions of the 'demographic' and 'healthy ageing' scenarios. The 'AWG reference scenario' is used in the multilateral budgetary surveillance at EU level. Specifically, it is assumed that half of the projected gains in life expectancy are spent without disability (i.e. without requiring care). The data projections are calculated by the AWG based on the System of Health Accounts (SHA), ESSPROS for the base data and a macro-simulation model based on detailed age-cost profiles and care recipient data directly provided by Member States as well as other data for the projections (source: Ageing Working Group and DG ECFIN). It should be noted that the data for the base year provides the only available estimate of total public LTC expenditure as a proportion of GDP and will differ for some

countries from the incomplete data included in the System of Health Accounts (where LTC(social) is not reported for every country)[1064].

**Public spending on LTC as % of GDP (risk scenario)*, base year 2019 and projected for 2030 and 2050** shows the current expenditure in the base year and the projections according to the 'AWG risk scenario'. This scenario keeps the assumption that half of the future gains in life expectancy are spent without disability/demand for care, as in the 'AWG reference scenario'. In addition, it combines it with the 'cost and coverage convergence scenario' which assumes convergence upwards of unit costs to the EU average as well as coverage convergence upwards to the EU-average. In comparison to the 'AWG reference scenario', this scenario thus captures the impact of additional cost drivers to demography and health status, i.e. the possible effect of a convergence in coverage and in real living standards on LTC spending. The projections are calculated by the AWG based on the System of Health Accounts (SHA), ESSPROS for the base data and a macro-simulation model based on detailed age-cost profiles and care recipient data directly provided by Member States and other data for the projections (source: Ageing Working Group and DG ECFIN).

**Public spending on institutional care as % of total LTC public spending*** shows what share of total public LTC expenditure the Member State pays for institutional care. The projections are based on to the 'AWG reference scenario' (source: Ageing Working Group and DG ECFIN).

**Public spending on home care as % of total LTC public spending*** shows what share of total public LTC expenditure the Member State pays for home care. The projections are based on to the 'AWG reference scenario' (source: Ageing Working Group and DG ECFIN).

**Public spending on cash benefits as % of total LTC public spending*** shows what share of total public LTC expenditure the Member State pays for cash benefits. The projections are based on to the 'AWG reference scenario' (source: Ageing Working Group and DG ECFIN).

**Government and compulsory contributory financing schemes as % of GDP, LTC Health**, is one of the main types of financing arrangements through which LTC services are paid for and obtained by people in the System of Health Accounts (SHA). The SHA uses the terms 'compulsory' in the sense of compulsory by law (or government regulation). It is mandatory for Member States to report on the health component (HC.3) of this expenditure. The purpose of care sets the boundary between LTC health and LTC social: care over a long or indefinite period aimed at dependent people, provided through medical and/or nursing, and personal care services (ADL – activities of daily living), is the basis for inclusion within the healthcare boundary (source: Eurostat, SHA, hlth_sha11_hchf).

**Government and compulsory contributory financing schemes as % of GDP, LTC Social**, is one of the main types of financing arrangements through which LTC services are paid for

[1064] The methodology is explained in detail in European Commission and EPC, 'The 2021 Ageing Report Underlying Assumptions and Projection Methodologies', *Institutional Paper* 142, November 2020. https://ec.europa.eu/info/sites/info/files/economy-finance/ip142_en.pdf

and obtained by people in the System of Health Accounts (SHA). The SHA uses the terms 'compulsory' in the sense of compulsory by law (or government regulation). This variable is not available for every EU Member State, as Member States report on the social component (HCR.1) of this expenditure on a voluntary basis. Therefore using only SHA data to estimate total LTC expenditure will lead to underestimates for those countries that do not report HCR.1. The purpose of care sets the boundary between LTC health and LTC social, irrespective of the provider: care with the primary purpose of enabling independent living and interaction with the environment, as in the case of home help or assisted living, is classified as LTC (social) and should be outside the health boundary (source: Eurostat, SHA, hlth_sha11_hchf).

**Household out-of-pocket payment as % of GDP, LTC Health**, is one of the main types of financing arrangements through which LTC services are paid for and obtained by people in the System of Health Accounts (SHA). A payment by the individual is not accounted as out-of-pocket expenditure if it is reimbursed by voluntary insurance, covered by the government or a NGO. In these cases, the payment for the care is not from the household's 'pocket'. It is mandatory for Member States to report on the health component (HC.3) financed by household out-of-pocket expenditure. The purpose of care sets the boundary between LTC health and LTC social: care over a long or indefinite period aimed at dependent people, provided through medical and/or nursing, and personal care services (ADL – activities of daily living), is the basis for inclusion within the healthcare boundary (source: Eurostat, SHA, hlth_sha11_hchf).

**Household out-of-pocket payment as % of GDP, LTC Social**, is one of the main types of financing arrangements through which LTC services are paid for and obtained by people in the System of Health Accounts (SHA). A payment by the individual is not accounted as out-of-pocket expenditure if it is reimbursed by voluntary insurance, covered by the government or a NGO. In these cases, the payment for the care is not from the household's 'pocket'. Member States report on the social component (HCR.1) of this expenditure on a voluntary basis. The purpose of care sets the boundary between LTC health and LTC social, irrespective of the provider: care with the primary purpose of enabling independent living and interaction with the environment, as in the case of home help or assisted living, is classified as LTC (social) and should be outside the health boundary (source: Eurostat, SHA, hlth_sha11_hchf).